Music and Disability: A Critical Investigation into Popular Musicians with Limbs and/or Digits which are Absent (LDA)

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September 2023

Word Count: 81,722

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Abstract

This thesis explores music-making by people with LDA (limbs and/or digits which are absent). LDA ranges from a partially-absent digit to a fully-absent limb. Therefore, a musician with LDA needs to negotiate their impairment by bypassing their absence or using alternative limbs and digits. Otherwise, the musician uses their affected LDA on their musical instrument directly or through an adapted prosthetic device. The study is framed by (music) disability studies, disability representational studies, approaches to LDA musicality, and organisational and institutional support encompassing LDA musicality.

The research is informed by a mixed-method approach through textual analysis, case studies, thematic analysis, semi-structured interviews, and surveys. The thesis is structured around three empirical chapters. The first involves the media and musical representation of four prominent famous musicians with LDA. Each musician navigates their personal, musical, and medical histories and may present their LDA in numerous ways across various music and media settings. The focus then turns to grassroots, professional musicians with LDA and the wide range of playing approaches that LDA musicality possesses. In addition, the investigation includes the organisational support available to assist musicians with LDA incorporating the origins, remit, mission statement, personnel employed, funding and how its distributed, and the most notable projects of the music and disability organisations studied. To supplement this information, representative figures from UK-based music education hubs are surveyed to understand the broader landscape of LDA musicality. Finally, the main findings are drawn together, highlighting the need (and demand) for greater sharing and connectivity to improve solutions within LDA musicality. This discovery is followed by the much-discussed potential of a centralised knowledge base which, although ambitious, could facilitate this common goal.

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Acknowledgements

I would like to thank Professor George McKay and Dr Mark Rimmer for their supervision and feedback throughout this process.

I would like to thank Dr Tim Snelson for his initial assessment of my proposed PhD, and Dr Hazel Marsh and Professor Timothy Blinko for being the internal and external examiners respectively for my viva.

I would like to thank my family for their continued and unwavering support, particularly my mother who has gone the extra mile.

I would like to thank all the interviewees who agreed to take part in my study: Dr Stephen Hetherington, Neill Duncan, Jennifer Petry, Jason Barnes, Jason 'Lefty' Williams, Tony Memmel, David Segal, George Dennehy, Valerie Thomforde, and Carien Meijer. In particular, there has been general support for this project, which I am incredibly grateful for.

I would like to thank the music education hub representatives who agreed to be surveyed being Yogesh Dattani and Tom Deam. Although the third representative requested anonymity, I would like to thank them for their contribution, even though it has not been included in the thesis.

Finally, I would like to dedicate this thesis to two tireless music and disability advocates who have sadly passed away during this process. These advocates are Neill Duncan (1957-2021) and Mark Goffeney (1969-2021). Their work has been a great inspiration for this thesis and music and disability advocacy, which I would like to be part of in the future, if I have the opportunity to do so.

Introduction

During my final year as an undergraduate, I sought a music-related topic for my dissertation. I am unsure of the precise origins of the pursuit, which led me to the area of study surrounding this thesis. I remember seeing pictures of several disabled musicians approaching their musical instruments in a multitude of ways, such as Ludwig van Beethoven, Django Reinhardt, and Stevie Wonder, be it through apparatus, bypassing their impairment, or through no adaptation respectively. Based on the numerous examples of disabled musicians I found through further research, I decided to do a scoping study of how disabled musicians have been able to play their musical instruments. Due to the enjoyment and success of this project, I had the ambition to follow up this research with a PhD thesis in the future. During a few years of seeking out exactly how this PhD study would materialise learning more about the construction and modification of assistive music technology and narrowing the scope of my focus, I faced rejection and unwanted responses to the structure of the PhD throughout. Ultimately, my decision was to research musicians with LDA (limbs and/or digits which are absent).¹

A question which needs to be answered is: why study LDA in isolation? Firstly, the subject area of LDA is narrow yet deep, which makes it suitable for a PhD thesis. Secondly, as I have continued my research into LDA, I have found that a term is prevalent, particularly in the United States, being 'limb differences'. Limb differences can be defined as any limb which deviates from the norm in terms of shape or form. However, I have not used this term for specific reasons. For musicians with 'limb differences', if a limb or digit is atrophied or paralysed, the affected limb or digit is most likely to be bypassed musically. My interest in LDA musicality is the *choice* of a musician with LDA either using their LDA *or* bypassing their LDA as part of their music-making. Furthermore, the term 'limb difference' is closely associated and concerned with congenital conditions affecting limbs. Whereas, I will not only examine musicians with congenital LDA; I will investigate musicians with adventitious LDA (both terms will be defined later in this section). Essentially, 'limb difference' is an

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¹ The term 'absent' is placed after 'limbs and/or digits' because ALD is an abbreviation for the genetic brain disorder, Adrenoleukodystrophy (The Stop ALD Foundation 2017).

umbrella term, which LDA fits within; a musician with LDA is a musician with a 'limb difference', yet a musician with a 'limb difference' is not necessarily a musician with LDA. It is worth noting that there will be inevitable crossover between the subject area of musicians with LDA and musicians with 'limb differences', as well as musicians with LDA and music and disability in general.

Another important question to be addressed is: why did I choose the word 'absent' rather than 'missing' limbs and digits? Although the two terms are relatively similar in meaning, there is a key distinction. The term 'missing' does suggest that something is not present where it is expected to be. However, there is the possibility that said 'something' has the possibility of returning in the future. Conversely, the term 'absent' or 'absence' indicates that something is not present, is lacking, or does not exist, without the prospect of returning at any time in the future. Therefore, in the context of this research, limb(s) or digit(s) are absent from birth, or become absent during one's life, be it by accident, a medical condition, or even by design for limbs and digits, which cause pain or discomfort with no chance of returning in later life.

The final question which needs to be discussed before moving forward is: why am I studying professional musicians with LDA rather than any musician (or person) with LDA? Although access and the creation and modification of assistive music technology are valuable for music and disability as a subject area, my study is interested in the physicality of LDA musicality. Inevitably, there will be crossover between access and physicality within disabled musicality and LDA musicality. For instance, Harrison and McPherson (2017) define two types of adapted instruments being therapeutic or performance-focused (p.270, see Frid 2019, p.4, and Samuels 2019, p.159-160). Instruments which employ broad, largely uncontrolled gestures without precision are not strictly performance-focused instruments; certain intricate musical techniques associated with traditional popular musical instrumentation are bypassed entirely. For fully performance-focused instruments, the nuanced musical techniques of popular musical instrumentation need to be navigated in a myriad of ways. This aspect will be of interest regarding musicians with LDA and their approaches to LDA musicality.

Now I will define LDA and its position in this research, since I acknowledge that it is not an established social or medical term. However, it has been explored outside of the field of music. Banerjee (1982) explains that absent limbs or digits are 'an impairment, not a health condition' (cited in Sears et al 2003, p.73). This impairment will remain for life and this state is unlikely to change dramatically (unless the impairment exacerbates, and further limbs and/or digits are absent due to an accident or amputation) (Sears et al 2003, p.73, and Lubet 2015, p.127). The effects of LDA can be slight or life-altering and be changed with the use of efficacious prosthetics (Ibid.). Based on this information, I have coined the term 'Musicians with LDA (Limbs and/or Digits which are Absent)'. This includes any absent limb, be it: an absent hand(s) or foot/feet; below-the-elbow/knee arm(s) or leg(s); above-theelbow/knee arm(s) or leg(s); or full limb(s) or, for absent digits: absent fingertip(s) or tip(s) of toe(s); partially-absent finger(s) or toe(s); or entirely absent finger(s) or toe(s). For example, conditions such as amelia (a congenital anomaly causing one or more absent limbs) will be eligible because the limbs or digits are defined as absent. Whereas, phocomelic limbs or digits (a congenital anomaly where the upper part of a limb is underdeveloped) will be exempt from detailed study because the limbs or digits have retained some form. Inevitably, exceptions will be mentioned when there is crossover between a limb and digit being absent and a limb and digit being musically 'incapacitated'. This is because techniques for musicians with a 'limb difference' may be germane to LDA musicality. For example, acoustic guitarist Steve Dalmas who did not use his strumming hand on the guitar due to a stroke, has a guitar method, which could be utilised by a onehanded guitarist with LDA (Dalmas 2015).

Musicians with LDA will fall into two distinct categories: 'congenital LDA' and 'adventitious LDA'. Congenital LDA can be defined as a person with LDA from birth. The word 'congenital' is an established term for defining aspects from birth. Adventitious LDA can be defined as a person with LDA after birth. The word 'adventitious' is applied because the absence has been caused by chance or external factors. This second term can range from an accident, an illness, or a medical amputation to relieve pain and discomfort. For example, at 20 years old, pop singer Viktoria Modesta asked doctors to remove the lower part of her left leg. The limb was injured from birth and she had several operations to mend it. Modesta states: 'There was a lot of uncertainty hanging over my health, [and] was determined to fix that so I could

do all the things I dreamed of' (quoted in Bailey 2014). The limb was removed and replaced with a prosthetic (for the majority of the time). The transition is described by Modesta as: 'going from economy to first class' (quoted in Ibid). Conversely, negativity and depression are understandable for musicians with LDA who previously had a healthy limb or digit. This is because the individual has become accustomed to having and using a limb and/or digit, which can be eradicated in an instant. Additionally, every part of using that limb and/or digit is hard-wired in the brain and, therefore, adjusting to accommodate this sudden change can be a difficult process (Lubet 2004, p.136). Therefore, the musician will need to assess their new situation based on a number of factors such as monetary conditions, when the musician became a musician with LDA, and the necessary volition to adjust.

It is important to note that several general factors will contribute to whether a musician with LDA will have an interest in performing professionally, which can be applicable to all musicians. These include: the professionalism of the musician; the financial situations and/or motivations; the stage of a musician's career (especially for adventitious LDA because of the sudden change); and the particularities and values of different musical genres, which may be beyond the control of the musicians. Another general factor to be considered for musicians with LDA is how well-practised the musicians are with their particular instrument and/or prosthetics. There is an intimation that the more practised the musician, the greater control and ability the musician will have of their chosen instrument and/or prosthetics (Siebers 2004, p.2).

In order to unpack the complexities of LDA musicality, this thesis is structured into six chapters. Chapter 1 establishes the themes through literature relating to LDA musicality and (music) disability studies. The sections will form the structure for the three empirical chapters being: the position of LDA representation within disability and music disability studies; the approaches of disabled musicians to their instrumentation and how this applies to LDA musicality; and the organisational and institutional support from practitioners in order to assist (aspiring) professional musicians with LDA and the potential of this support. Chapter 2 provides a methodology for undertaking this study including: which methods would be utilised for certain aspects of the thesis; the rationale for the inclusion of these

methods; and how these methods will assist in the research process. This mixed-method approach involves case studies, thematic analysis, semi-structured interviews, and surveys.

Chapter 3 explores the careers of four prominent popular musicians with LDA: Black
Sabbath and heavy metal guitarist with two partially-absent fretting fingers, Tony lommi;
The Grateful Dead and psychedelic rock guitarist and singer with a partially-absent finger on his strumming hand, Jerry Garcia; Def Leppard and glam metal drummer with a fully-absent left arm, Rick Allen; and 'bionic pop artist' and pop singer with a partially-absent leg who uses various visually-striking prosthetics, Viktoria Modesta. A case study approach will be adopted to explore the interconnection of these musicians' personal and musical histories and their medical conditions, as part of their media and musical representation.
Furthermore, issues will be explored surrounding: how a musician's chosen genre affects their media representation; the foregrounding and backgrounding of LDA in different media settings; the nature of LDA; and how the point in their life when they became a musician with LDA affected their media and musical representation.

Chapter 4 shifts the focus of the thesis to a number of grassroots musicians with a modest level of fame in comparison to prominent musicians from the previous chapter. This chapter is geared towards the playing approaches and instrument and device modifications of the newly introduced musicians. This chapter will team thematic analysis with semi-structured interviews. Experiential detail from six musicians with LDA will inform the variety of playing approaches to LDA musicality, with supplementary material from other musicians with LDA, or those closely related to LDA musicality. These musicians vary greatly musically, in terms of LDA, their genre, and in their approaches: one-handed jazz saxophonist, Neill Duncan; reggae fusion and 'cyborg' drummer with an absent forearm, Jason Barnes; folk and rock guitarist with an absent forearm, Tony Memmel; rock guitarist with an absent right forearm, Jason 'Lefty' Williams; armless multi-genre and multi-instrumentalist, George Dennehy; and classical pianist born with an atypical cleft hand (with two fully-formed digits on the right hand), Valerie Thomforde. This chapter will begin by finding the emerging patterns of playing approaches of musicians with LDA. Based on this, the playing approaches will be divided into three distinct sections across the spectrum of LDA musicality. These sections involve: how musicians with LDA adapt to conventional, unmodified instruments without

prosthetics; the use and creation of prosthetic devices to facilitate music-making; and the redesign of popular instruments and the creation of new instruments to emulate conventional design.

Chapter 5 focuses on organisational and institutional support, from the UK and USA, which could assist musicians with LDA. Both the methods of case studies and semi-structured interviews from representative figures of these organisations will be applied through this investigation. The case studies of music and disability organisations and the representative figures from these organisations interviewed are: co-founder of The One-Handed Musical Instrument (OHMI) Trust, Dr Stephen Hetherington; former CEO of Drake Music, Carien Meijer; co-founder of Cincinnati Adaptive Music Camp (CAMC), Jennifer Petry; and co-founder of Can-Do Musos, David Segal. To supplement this information, two UK-based music education hubs will be surveyed in order to find out the connections they have with music and disability organisations, and musicians with LDA, and how this interconnectivity could potentially be improved in the future. The two representative figures are Head of Ealing Music Service, Yogesh Dattani, and Music Development Lead for Teignbridge & Torbay, Tom Deam.

The concluding chapter summarises the main findings to emerge from chapters 3-5. These findings are underpinned by the prospect of improved information sharing and interconnectivity between the various practitioners across LDA musicality and potentially beyond, to supporting practitioners on the periphery of LDA musicality. This process informs the key considerations to improve LDA musicality in the future, including the potential for the creation of a centralised knowledge base. It will be interesting to discover over the course of this research if such an undertaking would be viable.

Chapter 1 – Literature Review of Music, Disability, and LDA

This literature review is divided into sections to lay the foundations for the research to follow into musicians with LDA and the specific issues and debates which need to be addressed. First, I will discuss the arguments and concepts surrounding disability representation and in turn, LDA representation. I will contextualise arguments within disability studies and music disability studies, which will allow for greater understanding of where musicians with LDA are positioned within these areas of study. This will be followed by an interesting aspect of LDA representation being the inclusion of prosthetics.

Prosthetics as an area of study will be examined in terms of theorising prosthetics; the aesthetic and functional concerns of prosthetics; the concept of wholeness; and the bionic/cyborg aesthetic. The final part of the first section will be concerned with musical representations of disability and the use of 'press prosthesis' to mask the effects of disability on music-making (see Lubet 2013). This will be followed by concepts, which cover both prosthetics and general LDA representation being passing, reverse passing, and masquerading.

The second section begins by exploring a manufacturing process which may be applicable to LDA musicality, being 3D-printing, as processes, materials, and sharing are inherent in the field. Then, a rare example of universal adaptation used in music: the one-handed piano repertoire of classical music, which has been used for over one-hundred years, will be explored. This will be followed by the concept of 'activist affordances' (Dokumaci 2023) being applicable for the adaptability of LDA musicality as a method for archiving various methods and practices (p.27). The final theme of this section is the importance of genres and sonic conventions on disabled musicians and the example of Oscar Peterson using 'instrumental prosthesis', which involves musicians within his own ensembles 'masking' the effects of his impairment in a compensatory fashion (see Lubet 2013).

The final section is concerned with organisations and institutional roles, which can assist musicians with LDA such as organisations dedicated to LDA musicality as a practice, the projects of other prominent music and disability organisations, which may have parallels,

and the use of other important authoritative practices such as teaching in music education, and the role of physicians and occupational and physical therapists. To finish, I will outline the three research questions which will guide the research methods and structure of the thesis to follow.

1.1 Representation and prosthesis

This section will investigate key concepts and arguments from disability studies and music disability studies regarding representation. I demonstrate how my research can draw on aspects of disability studies and music disability studies. Something which will become abundantly clear throughout this research is that music and disability are intersectional and can relate to many other fields. The key is to unravel the complexities of these intersections and extrapolate and define key information in the fields of disability studies and music disability studies. Intersectionality was a term devised by Crenshaw (1991, cited in Christensen-Strynø 2016, p.62). Intersectionality is the concept of multiple identities intersecting to create a new identity different from the constituent parts. Christensen-Strynø (2016) claims that disability studies scholars are now beginning to call for more intersectional analysis (p.62). Davis (2002) was of the opinion that 'disabled people are the ultimate intersectional subject' (cited in Goodley 2017, p.84 and p.87). Intersectionality is applicable throughout most of the everyday because we as people are defined in many different ways such as our ethnicity, nationality, and social class (Brown 2002, p.34).

The intricacies of music and disability as two separate entities is potentially even more convoluted. For example, a guitarist with an absent digit can be impaired every time they play the guitar; whereas, in everyday life, they would be able to carry out the vast majority of tasks with consummate ease (see Lubet 2011b, p.43-51). The intersectionality and fluidity of disability means that disability should be observed as a phenomenon, which can be experienced at any time and place. The instability of fluidity may cause problems for defining disability. However, this may be beneficial for the dominant group of able-bodied people. This lack of definition of disability would enable able-bodied people to gain knowledge and for disabled people to impart their own experiences with their own voice

(Davis 1999, p.502). Through the action of claiming disability, one is claiming the intersectionality which underpins their identity (Davidson 2008, p.224).

Shakespeare (1996) is of the belief that research should be a form of vindication for disabled people who view any substantial piece of writing affecting them (p.118). Lubet (2010) claims that any musician deserves the right to compose and play music, if they have the desire to do so (n.pag.). However, the stigma placed on many impaired musicians is based on the fact that impairment is perceived 'as a defect located in individuals that requires corrective treatments' (Longmore 2003, p.4). Despite the 21st century rhetoric of diversity, our society strives for 'bodily uniformity' as a form of normality via means such as cosmetic surgery and expectations for exercise and diet (Garland-Thomson 2005a, p.524-525). In summary, 'we expect medicine to wipe away all disabilities' (Ibid.). One of the reasons that bodies are standardised may be because disability is perceived as an ambiguous state, as supported by Murphy (1987, cited in Shakespeare 1994, p.295). This state is predicated on the fact that society cannot fully define and understand where 'long-term physically impaired' people fit within it (Ibid.). Garland-Thomson (2005a) suggests that biodiversity (a term used in biology for '[s]pecies, generic, and ecosystem diversity in an area') should be applied to humans as a new and informative method for redefining disability (Swingland 2001, p.377 cited in Garland-Thomson 2005a, p.525). This would allow those with different bodies to have a public space to showcase their bodies. Based on Garland-Thomson's argument, greater representation of both disability and human experience may be achieved if biodiversity is used in the field of music.

Informed by her work on representation, Garland-Thomson (2005a) asserts that one of the aims of disability studies should be 'to reimagine disability' (p.523). This particular aim explains how the representation of disability needs to be shown as an unjust system rather than what it is accepted as today. The narrative needs to be shifted to the first-person, rather than the third-person established narrative (Ibid.). The third-person narrative may be a reference to the overcoming narrative which has been accepted by numerous disabled people. The overcoming narrative can be defined as a narrative which tells the story of how a disabled person 'overcame' the adversity of their impairment in order to be successful suggesting that disabled people who do not 'overcome' are not successful (Silva and Howe

2012, p.175). This overcoming narrative is an important element of this discussion because it is an established narrative which gives power to able-bodied people. A reason why disabled people accept this narrative is because overcoming is a universal experience and is part of everyday life. Therefore, disabled people need to choose to accept this narrative and conform to it, or defy these expectations and create their own narrative, which could risk alienation or misinterpretation.

The reason the overcoming narrative exists is as a consequence of able-bodied people perceiving themselves as the standard (Garland-Thomson 1990, p.239 cited in Linton 1998, p.532). Able-bodied people impose standards for what disabled people can and cannot do (Goodley 2017, p.91-92). However, a problem with this ideology is that able-bodied people decide how bodies should be aesthetically and functionally (Davis 1999, p.504). Therefore, when a disabled person defies these expectations, this confuses and fascinates able-bodied people (Goodley 2017, p.91-92). Sometimes, disabled people exaggerate these expectations in order to gain acceptance (Siebers 2004, p.13). One method which is an alternative to the overcoming narrative is to normalise impairment as something which can be experienced by all people to some degree (Shakespeare and Watson 1996, n.pag.).

For people with impairments, the body itself tells the audience the story, which is why the body is especially powerful when linked to visual media (Smith and Sparkes 2008, p.18-20 and Shildrick 1999 cited in Goodley 2017, p.85). The overcoming narrative is likely to be the source of the vast majority of disabled people's stories because the transformation of the person is a more palatable story for the public, rather than challenging established societal norms. As Siebers (2004) describes, the overcoming narrative is 'a metamorphosis from non-human to human' (p.13). Therefore, for a musician with LDA, is there a way to transcend their disability and bypass the overcoming narrative or would this be part of the supercrip narrative? (Linton 1998, p.532 and Lubet 2004, p.134). Typically, the supercrip narrative means, 'someone with a disability who gains attention for 'mundane accomplishments'' (Buck 2023, n.pag). Kana (n.d.) extends this narrative to the 'glorified supercrip' being someone with a disability who accomplishes, 'feats that even non-disabled persons rarely attempt' (cited in Ibid.). When comparing congenital LDA and adventitious LDA, the overcoming narrative will be different for each category. This is because congenital

LDA is not strictly overcome as the impairment has always existed; whereas, for adventitious LDA, there is an obvious change from being able-bodied to physically disabled.

In terms of representation, if the musician with LDA is not in control of the visual media they are being displayed on, the overcoming and supercrip narratives may be unavoidable because as these success stories are easily understandable, this may be the only method for telling their story or showcasing their LDA. Sometimes, stories highlighting disabled people focus on those with exceptional talent. Buck (2023) explains that the overcoming narrative means that a musician must, 'overcome their disabilities to attain artistic mastery and/or commercial success' (n.pag.). This is because ability supersedes disability (Siebers 2004, p.16). However, these stories can be exaggerated or fabricated. Regardless of whether these stories are true or false, they fall under the bracket of the 'supercrip narrative' as the very action of doing may be deemed extraordinary by able-bodied audiences. In order to shift the control of the narrative to the individual, the disabled person needs to construct the narrative or it needs to be constructed by supportive people with the best interests of the person at heart. This would allow disabled people the opportunity and means to tell their own unfiltered narrative based on their own experiences of impairment and how these experiences pertain musically and aesthetically.

An intriguing area of LDA media representation is the visual presentation of prosthetics or limb absence. Prosthetics are simultaneously a substitute and an extension of the body (Sobchack 2010, p.62). Merleau-Ponty (1962) states that: 'substitution is the impulse of being-in-the-world... it acts only for bodily recognition, it is experienced as an "open" situation' (p.78, cited in Sobchack 2010, p.63). This suggests that prosthetics are seen as the obvious substitution for an absent limb and/or digit because prosthetics comply with the normative societal standards. However, the choice of not using prosthetics is still accepted as a viable alternative because one can readjust to compensate for this perceived absence. Prostheses can be beneficial for self-esteem because people with LDA can view themselves with a 'complete' body. This may be due to a person having had a full limb and/or digit for many years and this absence being a reminder of one's mortality, or having not used prosthetics for their LDA for years, giving them a new form of 'empowerment' (Alderson 2015, p.96 and Davidson 2008, p.222). Although in most cases it can seem that prosthetics

are just a replacement, athlete and amputee Aimee Mullins (2011) is of the belief that prosthetics can be used as a tool by the person with LDA to create their own narrative in an emancipatory fashion (cited in Rembis 2013, p.132-133). Prosthetics do not necessarily have to be life-like or extravagant for purely aesthetic reasons. The aesthetic concerns may be imperative for musicians with LDA who want to use visual media to highlight their prosthetics or their absence.

When theorising using and not using them, prosthetics are seen to be part of the medical and rehabilitation models (as restoring health and/or established support); whereas, not using prosthetics would be considered to fit within the social model (changing or conforming to public perception) (Davis 1999, p.506). I would claim that prosthetics also fit within the overcoming and supercrip narratives because they are seen as a 'cure' for a person's impairment; whereas, the use of no prosthetics would be considered passing (being identified as able-bodied) if hidden, or as a source of intrigue, if visible (Siebers 2004, p.11-12). A prosthetic may detract from the impaired limb or digit and towards the prosthetic itself. Prostheses are an acceptable replacement; whereas, 'disabled limbs spark curiosity and anxiety' (Ibid., p.12). However, if these prostheses are ambiguous aesthetically or functionally, they can detract from the impairment. Prosthetics become established in their certain forms and appearance and therefore, any change can cause intrigue, especially when the prosthetic is not named as such. This can potentially reduce prosthetic wearers to be defined solely for their prosthetic, however, they can redefine disability if successful (Ibid., p.12-13). Wholeness of the body is redefined by prosthetics. Prosthetics complement the ideology of disability being an ambiguous state due to the changing of the contours of the body, which defies the expectations of how to define wholeness (Wigley 1991 cited in Iverson 2016, p.158). Mitchell and Snyder (2000) claim that prosthetics are favourable as a form of variance (cited in Iverson 2016, p.159). However, if the disability is perceived to be too far from the welcomed deviation, prosthetics may be used to remove the perceived deviation entirely (Ibid.). The implications of representation suggest there are an array of methods for presenting LDA, which can be perceived and interpreted in numerous ways based on preconceived notions of disability.

Manderson and Peake (2005) suggest that the fact some disabled people choose to wear an extravagant prosthetic over a life-like prosthetic means that they are willing to change perceptions aesthetically yet conform in terms of prosthetic function in line with normative standards (p.238). This means that the use of life-like or extravagant prostheses is a conscious decision based on the wants and needs of the disabled person. Conversely, some amputees choose not to wear any prosthetics whatsoever. In the field of Sport and Disability, a disabled sportsperson claims that: 'Without prosthetics I feel whole. More pure and whole. I am just myself-no outside engineering put in. One, complete, whole' (Ibid., p.239). The museum exhibition-esque work of the armless Mary Duffy, who transforms herself into the Venus de Milo is accepted because it is 'the quintessential icon of female beauty' (Garland-Thomson 2000, p.336). This performance changes the disparaging misrepresentation of terms such as 'congenital malformation' to 'being whole, complete and functional' (Ibid., p.337). Wholeness may have implications in both representational forms and approaches to LDA musicality such as feeling 'whole' with prosthetic function.

One musician with LDA may feel it is paramount that they use prosthetics in order to function musically; whilst another may be in a position to navigate function around this and are thus musically whole without. When defining prosthetics, Lubet (2013, p.154) believes there is a binary between the 'literal' and the 'metaphorical'. The 'literal' prosthesis is the easily recognisable manufactured substitute for the absent limb and/or digit (Wills 1995, p.218 cited in Lubet 2013, p.154). In contrast, 'metaphorical' prosthesis can be related to prosthetics that defy expectations, functionally, aesthetically or perhaps even emotionally in the eye of the onlooker (Mitchell and Snyder 1997, p.17 cited in Lubet 2013, p.154). This definition can be expanded upon with the bionic/cyborg aesthetic being used by disabled people to suggest that these types of prosthetics are an improvement on human limbs as a form of empowerment, thus intriguing the public (Mitchell and Snyder 1997 p.8 cited in Lubet 2013, p.154). When considering musicians with LDA, the use of the bionic/cyborg aesthetic will impact LDA representation both musically and visually. In addition to this, musicians with LDA use life-like (literal) prosthesis and/or extravagant (metaphorical) prosthesis for various aesthetic and functional reasons.

Prosthesis may crossover into the bionic/cyborg aesthetic. As Haraway (2000) points out, the cyborg is 'a hybrid of machine and organism' (p.291) and 'a creature in a post-gender world' (p.292). The cyborg aesthetic twinned with cyborg imagery could be a method of reimagining disability (Garland-Thomson 2005a, p.523). Removing the ambiguous state of disability could potentially be achieved through the use of cyborg imagery (Haraway 2000, p.316). Presenting musicians with LDA through the prism of the bionic/cyborg aesthetic (both aurally and visually) could be a viable alternative to presenting disability as ambiguous rather than in the dominant, oppressive form. The bionic/cyborg aesthetic may be desirable for disabled people because this can potentially remove the 'disabled' label. This is predicated on pop culture imagery having accommodated 'bionic' and 'cyborg', which in turn can allow disabled people to be accepted by able-bodied people (Alderson 2015, p.95 and Goodley et al., 2012 cited in Christensen-Strynø 2016, p.61). For example, one disabled actor on an advert used a prosthetic leg, which he called his 'Terminator leg' (Haller and Ralph 2006, n.pag.). In addition, in the video for 'Prototype', Modesta is perceived as 'the human prototype' in the 'establishment of a new world order' (Christensen-Strynø 2016, p.69). The problem with the bionic/cyborg aesthetic is that this can perpetuate the idea of the aforementioned 'supercrip' narrative. This can mean that the public view is distorted and the effects of an impairment can be exaggerated dramatically, despite the limitations potentially only being slight. Based on previous information, able-bodied people may expect disabled people who use prosthetics to choose bionic prosthetics rather than life-like prosthetics (Alderson 2015, p.97-98). This potentially overlooks the physical and mental aspects of choosing to use, or not use, prosthetics (Siebers 2008, p.63 and Kafer 2013, p.105 cited in Christensen-Strynø 2016, p.63).

Representation and expectation can be complicated further with genre expectations for disabled musicians. Straus (2011) introduces the idea that disabled musicians usually need to 'pass an implicit test of authenticity: the public wants reassurance that someone so obviously impaired could really have produced the work ascribed to him or her' (p.25). Although Straus (2011) is concerned with classical music, this 'authenticity' could easily be applied to popular music because disabled musicians are usually judged for how they 'overcame' their disability in order to play their musical instrument of choice and perform on stage. The music or performance is not judged in the same light as it would be for a non-

disabled musician. Regarding authenticity, in order to understand the music presented to us, it should exhibit and question authenticity because our experiences are a prominent factor for musical value (Middleton 1990, p.127 cited in Moore 2002, p.212). In addition, authenticity may include certain instruments being used in order to be classified or part of a certain identity or genre and the singer being a spokesperson for the part of society from which they have come (Gilbert and Pearson 1999, p.164-5 cited in Moore 2002, p.209). Musicians with LDA will need to find their own way of integrating themselves within these expectations or disregarding them in an acceptable manner, whatever that may be. In order to be relatable, a singer with LDA may choose to sing of a metaphorical loss rather than a literal loss of LDA. This is because audiences have expectations for performances such as instrumentation, lyrics, the appearance of the band, and certain musical and stylistic idioms.

I will explore how passing can take many forms in music and visual media and performance. This will be theorised by the theory of staring; the decisions and implications of passing for disabled musicians; and what Lubet calls 'press prosthesis', in the career of Oscar Peterson and his presentation to the general public (Lubet 2013, p.168-176). Performance by a disabled person allows for their narrative to be visualised (Garland-Thomson 2000, p.334). As Garland-Thomson (2000) states: '[t]he disabled body on view *is* the performance' (Ibid.). Therefore, a disabled person can attempt to answer the question: 'What happened to you?' through performance (Ibid.). By demonstrating what the disabled body can do musically, a different aesthetic is created explaining how the performer is able to play their instrument and achieve sonic results. These performances allow the musician to display themselves in a positive fashion and protest the preconceived stereotypes (Ibid., p.335). The disabled person can create their own narrative and reconfigure the imposed non-disabled narratives.

Garland-Thomson (2006) theorises this through the staree/starer relationship. This theory is more concerned with face-to-face interaction. However, this can easily be extrapolated for music performance and visual media. The performer (staree)/audience (starer) relationship has many different stares. Unwanted stares can be described as: 'arrested staring' (where the starer is stunned by the visual of the staree's appearance) and, as Roche (1999-2006) coins, 'separated staring' which causes the starer to feel threatened and fearful of the staree (cited in Garland-Thomson 2006, p.186-187). A form of staring for these

performances, which can be welcomed, is engaged staring. This type of staring is more of an understanding of what is being viewed (Garland-Thomson 2006, p.188). Virtual staring from popular media such as photographs, films and digital imaging separate the viewer from the viewed by changing the stare. This occurs because the starer has no responsibility with the object of the stare and the starer and staree will not encounter one another (Garland-Thomson 2005b, n.pag.). When regarding static photography such as album covers and publicity shots of bands, 'it summons up a narrative, a prosthetic for imaginative work' (Featherstone 2010, p.198).

Based on these considerations, disabled musicians may choose to pass as able-bodied. However, this position is very convoluted and can be perceived as hiding the indicators of impairment to avoid the stereotypes which surround disability (Brune and Wilson 2013, p.1). Despite the issue of passing being an important part of negotiating disability identity, Brune and Wilson (2013) acknowledge that the field of disability and passing has not been addressed by scholars to a satisfactory level (Ibid., p.2). Passing can be a source of empowerment because it reduces the aforementioned 'overcoming' narrative (Ibid., p.4-5). Disabled people, however, cannot overcome their own embodiment (Rembis 2013, p.134). Rembis (2013) suggests that the 'overcoming' narrative will never be removed entirely because everyone can relate to it to some degree (Ibid.). Passing could allow disabled musicians to deviate from the overcoming narrative and be used as a method of creating new narratives (Schlossberg 2001 cited in Brune and Wilson 2013, p.5). Alternatively, the disabled person can use narratives based on their own life, which can dispute how they present themselves (Ibid.). Passing is similar in nature to any performance because in order to be perceived favourably, it needs 'both a skilled actor and a receptive audience' (Wilson 2013, p.31). This suggests that despite all efforts made on the part of musicians with LDA and the people who support them, the audience needs to be willing to accept these musicians. This may be an insurmountable barrier for those who will never be accepting of disabled musicians for whatever reason.

Although passing may seem, based on previous evidence, to be a good decision, it is not progressive because passing does not help able-bodied people understand the corporeality and mentality of being and living as a disabled person (Ibid.). Passing is a problem because it

only acts to make the audience comfortable and it restricts our understanding of the experiences of disabled musicians and the music performed (Cain 2010, p.748). This raises the question of: why is passing a technique used by disabled musicians? This is because disability can be perceived as a failure in the 'performance of health' and thus a 'failure of self-representation' (Ibid., p.749). This creates the notion that to perform better means to have a healthy, fully-functioning body. When making a comparison to musicians with LDA, it is worth noting and defining Howe's (2016) standardised version of the 'normal performance body', which: 'usually possesses all limbs, with above-average hand and finger size, lung capacity, and strength, among other qualities' (p.196). As the bodies of musicians with LDA do not conform to the expected 'possession of all limbs', this is typically why LDA musicality deviates from the norm. The disabled musician does not request the 'appropriate accommodations because to acknowledge their disability is to acknowledge their weakness, their difference, what separates them from their colleagues, what makes them no longer musicians.' (Ibid.).

Passing may seem to be a purely visual phenomenon; however, it has been achieved within a musical and editorial context. Lubet's (2013) work on jazz pianist Oscar Peterson who had a stroke which affected his left side, introduced us to the term 'press prosthesis', which is an aesthetic prosthesis, created by commentators trying to conceal the extent or existence of impairment (p.168). The reason 'press prosthesis' was used was to combat the fact that Peterson's impairment was visible. Therefore, people who understood his situation could manipulate his audience and some reviewers. For example, Peterson's publicists annotating his post-stroke albums claimed that his impaired left side from his stroke had little effect on his technique or failed to mention it (Ibid., p.157 and p.168). Of the twelve post-stroke albums of Peterson, five omitted his disability. The other seven discs all praise Peterson for 'overcoming' his impairment to play the piano successfully again. However, this is not accurate because Peterson did lose most of the function in his left hand and essentially became a one-handed player. This fact should not detract from his talents; however, this could be a deterrent for lovers of Peterson's pre-stroke music or less marketable for the general public (Ibid., p.169, p.171-172, and p.174).

In interviews, Peterson himself would be more earnest about his loss and adjustments, which is a positive way for the audience to understand his disability; whereas, the 'press prosthesis' meant that Peterson did not advocate for disability change, which could have been progressive for the disabled community (Ibid., p.171). One such example is in his memoir 'A Jazz Odyssey' (2002), which only mentions his stroke in a chapter title and two paragraphs (Ibid.). This omission fails any musician who may be attempting to return to music after a life-altering event because it suggests that one's outlook or musicianship should be unaffected (Ibid., p.171, and p.177-178). Lubet (2013) explains that when listening to Peterson's post-stroke music, his impaired hand is highlighted when the listener knows exactly what to listen out for. However, if unaware of the impairment or believing it had a lessened effect, listening out for something which is missing is not achieved (Ibid., p.168). A different example by Lubet (2013) tested this by subjecting a well-versed jazz audience to the music of Horace Parlan, a pianist with polio affecting his right hand, with some of the audience being aware of Parlan's oeuvre (Ibid., p.169). This resulted in the audience not being conscious of Parlan's impaired right hand or its impact on his technique (Ibid.). Lubet (2013) himself found it difficult to decide whether to market his own music as an impaired artist or pass as able-bodied (Ibid., p.178-179). This, along with the rest of the evidence in this section and more general factors affecting all musicians, demonstrates how difficult it is to decide whether to pass or not.

A representational phenomenon explored by Siebers (2004) is called 'disability drag' (p.16). The term 'disability drag' compares acting disabled with transvestism making disability appear optional and, in some circles, taboo, which may be the intention of Siebers' term. Examples of what Siebers (2004) coins 'disability drag' can be found in the exaggerated and commercially successful performances of able-bodied actors playing disabled roles in films. Although this presentation may bring disability to the public sphere, it does not present disability in an authentic manner. The audience judges the performance on how well the able-bodied actor performs the disability. Furthermore, the audience is aware that once the able-bodied actor has finished in the role of the disabled character, they will instantaneously become able-bodied and thus 'cured' (lbid., p.18). This is further complicated by musicians appropriating disability, potentially as a form of hyperbole. McKay (2013) postulates this with the examples of Roger Daltrey, Morrissey, Kurt Cobain and

Gabrielle who 'performed' different mental and physical disabilities in various media including in film, through music recordings, on stage, and through speculation in the press (p.11-12).

When disabled people exaggerate their own disability, this is what Siebers (2004) terms the 'masquerade', which is the antithesis of passing (p.19). The ideology of the 'masquerade' is to try to create new narratives from the existing stereotypes in society. These over-zealous actions may make uncomfortable viewing for conservative audiences; however, if change is to be achieved, this may be the best course of action (Ibid., p.19-20). Visual imagery has the potential to present disability in new and exciting ways for mainstream audiences. In summary, using certain prosthetics, musical adaptive devices and instrumental modifications can foreground and background disability, based on the preferences of the musician with LDA and/or certain types of visual media they are using.

1.2 Approaches to LDA musicality

Prosthetics and adaptations for musical instruments are more likely to be for functional and practical, rather than aesthetic, reasons. The human hand is a fantastic and multifunctional tool for control, grip and touch. Therefore, could the augmentation of the human hand (or arm, leg, or foot) be a way of creating alternative and fascinating new methods for playing musical instruments, which could improve efficiency, or would this be deemed as removing some of the skill required to perform musically? (Alderson 2015, p.94 and p.97). The many options surrounding prosthesis in both aesthetic and functional terms has interesting implications for the position of disability in popular music (Lubet 2013, p.155, and Ott 2002, p.32-33).

Examples of musical prosthesis include instrumental assistive devices for LDA or specifically-designed prosthetics for musical performance. Later in this section, I will explore the only universal provision which can be used by musicians with LDA playing the piano—the one-handed piano repertoire of classical music, which can be described as 'repertoire prosthesis'. Finally, I will demonstrate how in Lubet's (2013) work on Oscar Peterson,

prosthesis can move beyond tools and can include fellow musicians as a form of compensation (Ibid., p.178-179). This part of the section focuses on instrumental prosthesis and raises some of the considerations facing musicians with LDA when choosing an instrument or a piece of technology to use based on literary works to be outlined. These include cost-effectiveness, accessibility, and the challenges in playing an adaptive instrument versus a conventional one. Howe (2016) suggests how some assistive tools have been universally accepted for numerous musicians such as page turners for notation, shortened stop lengths for cellos (which shorten the strings for players with smaller hands and reach) and adjustable heights for piano benches (p.200). The reason that certain adaptive devices and methods of playing have been widely accepted over specialised adaptations can be related back to the parallels of everyday adapting. Dokumaci's (2023) theory of the 'habitus of ableism' refers to an 'unknowingly incorporated set of bodily dispositions and skills and, necessarily, their affordances that have become established as the way of moving, sensing, and behaving in the world, negating all other alternatives' (p.20).

As already noted, in terms of distinctions between instruments, Harrison and McPherson (2017) suggest that instrument playing has two categories: 1. therapeutic and 2. performance-focused (p.270, Frid 2019, p.4, see Samuels 2019, p.159-160). There is a dichotomy between access to playing and being able to express one's self on a musical instrument, which needs to be negotiated by a musician with LDA. As professional and aspiring musicians typically adapt to an instrument or build DIY devices to enable musicmaking, the performance-focused is more inherent. In Buck's (2023) investigation into amputees in southern roots music, he provides several examples of banjo players and fiddlers such as "Uncle" Frank Rayborn, H. F. Brock, Reuben Phares, Luther Caldwell, and Emory Martin finding their own ingenious DIY solutions for playing their instruments (n.pag). These modifications include: a pole attached to a chair to lean the neck of a banjo; putting the instrument upside down; placing a metal strip on the banjo's neck; fastening or holding a fiddle bow between the legs; playing a banjo on the floor using feet, a stump and teeth; playing the banjo with one foot and with the other hand; and the utilisation of pedals for bowing the fiddle (Ibid.). Buck (2023) highlights how ingenuity is at the heart of southern roots music: '[f]ocus typically rested squarely on the inventive adaptions amputees

deployed to play their instruments' (Ibid., see Ott 2002, p.16 and p.31). Even genres of music can have an association with LDA. As Buck (2023) states: 'Ironically, limb loss, as a disability defined culturally by bodily absence, has been conspicuously present in much southern roots music' (n.pag.).

Although I have highlighted the various methods and devices disabled musicians have used, this ingenuity has parallels with the mindset required by disabled musicians for navigating everyday life. Dokumaci (2023) coins the navigation of everyday life as 'activist affordances': "affordance" means an action possibly shaped by the reciprocal properties of the organism and the environment, and "activism" means world-making' (p.5, see lbid., p.7). Dokumaci (2023), who has rheumatoid arthritis, explains that: 'my everyday life turns into a stage for what I would describe as *choregraphing the dance of avoiding pain*' (lbid., p.1). In keeping with the adaptability of LDA musicality, 'activist affordances' are performative in nature: '[a]ctivist affordances use performative microacts/-arts through which disabled people *enact* and bring into *being* the worlds that are not already available to them, the worlds they need and wish to dwell in' (lbid., p.5). Based on the adaptive ingenuity of southern roots musicians, these solutions could be described as musical 'activist affordances'.

Additionally, Dokumaci (2023) incorporates the use of the term 'shrinkage' meaning that the options available to a disabled person in a living environment (or a musician with LDA with a musical instrument in a performative space) are few and far between which signifies adaptability is borne out of 'necessity': 'It is exactly this *necessity* that I want the concept of activist affordances to articulate' (Ibid., p.7). Furthermore, 'activist affordances' involve the person taking it upon themselves to make changes or utilise household materials, which cannot be replicated by designers and makers in specialised spaces and with state-of-the-art equipment, particularly as these experts have no reference points and these processes are individualised (Ibid., p.9, p.13, and p.24). To avoid these issues, Dokumaci (2023) highlights that sharing these methods is paramount: 'I wrote this book because I do not want our activist affordances – the making up, making real, and making do – to go unrecognized anymore' (Ibid., p.27).

Regarding universality, the piano itself is an instrument which has been used by numerous musicians with LDA. Famous and prominent classical musicians were involved in the development of what is regarded as the modern piano. In his later life, Johann Sebastian Bach was an agent and provided feedback to innovative manufacturer Gottfried Silbermann (Badura-Skoda 2000, p.10-11 and p.13-16, and Drozdov et al 2008, p.780). Silbermann pioneered the damper pedal which is key to one-handed piano because it 'masks' the jumps which are required (Drozdov et al 2008, p.780). The popularity of the piano advanced further still in the second half of the 18th century, with Wolfgang Amadeus Mozart using the piano for his sonatas and concertos, as well as Ludwig van Beethoven and Franz Joseph Haydn being the first composers to use Broadwood pianos with a range exceeding 5 octaves (Ibid., p.781). This suggests that if high-profile musicians promote an instrument, which can be used by all, disabled musicians will have the option to learn the instrument rather than only being able to adjust and adapt their technique on bespoke instrumentation. During the Industrial Revolution, the piano increased from 5 to 7 octaves and incorporated three pedals (sustaining, soft, and sostenuto), which created greater musical richness (Ibid., p.780). The piano, unlike string instruments, creates no mechanical restraints for LDA. This is because music for the piano can be written for any number of hands, feet, and digits. The only limitations are imposed by the standards of the pianist (Ibid., p.781). This explains how the universal accessibility of the piano can be beneficial to any musician with LDA.

Over the last thirty years, technology has become more affordable and, with the introduction of virtual studios, any musical instrument can be replicated more easily, without the need to play the instrument itself. The design and manufacture of any technology is market driven. However, the marketability of disabled music technology is far smaller (Challis 2009, p.1 and p.4). This could explain the bespoke nature of adaptive instruments being not easily affordable and not mass produced. There are examples of unconventional instruments which were not designed specifically for disabled musicians, yet have useful features for them. Instruments can be designed for universal accessibility and thus incorporated into popular music. The Theremin has been used in popular culture especially in science fiction, which increased its popularity. However, it has also been used in popular music by musicians and bands such as Led Zeppelin, Goldfrapp, Marilyn Manson, David Gray and Timbaland (Ibid., p.11). Another example is the Tenori-On which uses a

sixteen-by-sixteen grid of LED switches responding to real-time musical events. It has been used in popular music performances by artists such as Björk (Ibid., p.12). The use of these accessible instruments would allow aspiring musicians with LDA to learn on an instrument which caters to their needs and can be compared to other impaired musicians using the same instrument in contrasting ways.

There is seemingly a lack of performance-based customised instruments for LDA, with many adaptive musical instruments having no vibrotactile feedback and short lifespans (Frid 2019, p.1, p.3, p.12, and p.15). A potential solution for adaptive device and instrument making is through the growing industry (described as 'the new industrial revolution') (Kantaros and Diegel 2018, p.1511) for production: 3D printing. 3D-printing, or more accurately, 'additive manufacturing' (lbid., Thierer and Marcus 2016, p.807, and Campbell et al. 2011, p.1), involves objects being added layer-by-layer rather than traditional subtractive manufacturing, which takes a larger form of the material, such as wood, and reduces the material down to the shape of the object (Thierer and Marcus 2016, p.807-808, Kantaros and Diegel 2018, p.1511, and Campbell et al. 2011, p.1 and p.3). The previous 'mass-production' (Thierer and Marcus 2016, p.807) will be replaced with 'mass customisation' (Campbell et al. 2011, p.9), based on the needs of the user at a much-reduced cost. The manufacturing is also brought to average citizens, allowing for homemade and classroom adaptations to be made, as opposed to previously only being produced in factories (Thierer and Marcus 2016, p.807, p.812, and p.849 and Campbell et al. 2011, p.5).

Furthermore, 3D-printing allows for easier, cheaper printing in a single process. This means on-demand production through local printing in the country of consumption can be achieved, rather than being made in a factory on the other side of the world (Thierer and Marcus 2016, p.807-812 and Campbell et al. 2011, p.2, p.5-7, p.9-13). 3D-printing is defined by being highly customisable and 'rapid prototyping' of designs including producing through transferable files such as Stereo Lithography (STL) for 3D-printing, which can be likened to the Portable Document Format (PDF) file for 2D-printing (Campbell et al. 2011, p.1-2, and p.4). For less complicated objects, there have been examples of vast numbers being produced such as 3D-printed prostheses and 10 million 3D-printed hearing aids (Thierer and Marcus 2016, p.810-811 and p.840-846). Another 'mass customisation' example includes

100,000 patients with custom dental braces being fitted perfectly for each user (Campbell et al. 2011, p.4). In sharp contrast, it has been suggested that fully 3D-printed instruments require the use of special tools by highly-skilled craftsmen in specialised workshops, as well as having high purchase and usage costs (Kantaros and Diegel 2018, p.1512, Samuels 2019, p.161, and Samuels and Schroeder 2019).

The key to manufacturing for music-making is the collaboration between the musician and the instrument maker/designer throughout the whole process (Samuels 2019, p.155, Bell et al. 2020, n.pag, Samuels and Schroeder 2019, p.479, Woldendorp and van Gils 2012, p.236, and Lebler and Hodges 2017, n.pag). 3D-printing allows for more effective collaboration through the re-invention of many older products and for new innovations: due to being able to print virtually any object on a computer; better final products; designers being able to print ideas instantaneously; prototyping in their own spaces; and iterations being constantly updated (Kantaros and Diegel 2018, p.1512, p.1520-1521 and Campbell et al. 2011, p.1-6, p.10-12). Bell et al. (2020) claims that manufacturing should not be 'one-size-fits-all' (n.pag). Rather, the philosophy should be 'one-size-fits-one' and then extend from there (Holmes 2018 cited in Ibid., see Samuels 2019, p.154, p.157-159 and Frid 2019, p.2-3).

Another consideration for approaching a musical instrument as a disabled musician involves the conventions of musical genres. The multifaceted nature of musical genres in terms of acceptance and ability to succeed for disabled musicians is linked to the notion of authenticity. Authenticity is interpreted by the audience and as Rubidge (1996, p.219) states: 'authenticity is ... not a property of, but something we ascribe to a performance' (cited in Moore 2002, p.210). Musicians with LDA who adapt their technique with no prosthetics on traditional instrumentation can be easily understood by the general public. Musicians who use prosthetics in order to play on traditional instruments will probably be perceived as acceptable because the prosthetic supplants the absent limb and/or digit. However, if a musician with LDA plays on a bespoke instrument, this can cause intrigue because, for the majority of people, it is not musically relatable and is seemingly complex. If the instrument played is not too dissimilar to traditional instrumentation in presentation and design, this may be deemed as an acceptable variance from the traditional instrumentation. However, if the instrument is bespoke in both presentation and design,

this may prove more difficult to accept for the audience, especially if it is hard to comprehend how the instrument is played. If musicians with LDA can prove their proficiency or virtuosity on a bespoke instrument, then this may be approved by the public. One method which has been used by musicians is appropriation. This can be achieved by musicians covering songs in a genre they can relate to, or on a subject they can identify with. For musicians with LDA, the use of emotional pain can potentially substitute the physical pain they have or may be enduring (Coleman 1994, p.31 and Middleton 1990 cited in Moore 2002, p.215-216). The authenticity of a performance questions who is being authenticated. This then raises the issue of a musician potentially being inauthentic to try to gain acceptance from the public. This may include a disabled musician attempting to pass as able-bodied or downplaying the extent of their impairment.

Lubet (2015) uses the term 'social confluence' because individuals have many aspects to their being and thus can identify themselves as being part of various categories (p.124). Therefore, a musical genre can be compared to a country in the world and thus acceptance and exclusion can be complex (Ibid., p.128). Classical one-handed pianists Gary Graffman and Leon Fleisher had less impaired hands visually compared to Horace Parlan; however, jazz allowed Parlan to flourish and optimise his potential with creative freedom (Lubet 2010, n.pag.). This is even greater with the genre of punk because the genre has been perceived as the 'anti-aesthetic' in popular music infiltrating the mainstream (McKay 2016, p.226-245). McKay (2016) demonstrates how punk has used disability and used it in a marketable way in the guise of the 'exotic outsider' (Ibid., p.232-233). Lubet (2015) criticises classical music for only allowing classical musicians to use their unimpaired hands. The impaired hand is 'hidden, nonexistent or even functionally amputated' (p.136). However, if a musician with an impaired hand can utilise and optimise the unimpaired hand to its fullest, that may be more beneficial than attempting to use an impaired hand, which could have pain-related issues.

Although many other genres have embraced musicians with LDA for their talents through more lenient barriers to entry, it is only the demanding field of classical music which has incorporated accommodations which directly aid musicians with LDA with the one-handed piano repertoire. The repertoire could be described as 'repertoire prosthesis' (see Lubet

2013), which can also be a method of changing and enhancing the technique of musicians with LDA. Drozdov et al (2008) are of the belief that being an amputee can be hugely detrimental to the creativity of these musicians (p.780). The concert pianist Ivan Ilic states the difficulty of playing with one hand: 'Playing with both hands masks the deficiencies of each hand, until one plays with one hand... It's like playing a different instrument' (quoted in Pinchbeck 2016, p.3). This is of great importance because this repertoire attempts to create the illusion of two hands playing the piano, when in fact only one hand is required for similar aural qualities expressed within the piano itself (Lubet 2015, p.128). The one-handed piano repertoire is not designed specifically for pianists with LDA. Edel (1994) states that one-hand piano compositions are created for four reasons: '(1) technical development, ...for better two-handed playing; (2) injury of one hand; (3) compositional challenge; and (4) as a display of virtuosity.' (p.3-11, cited in Lerner 2006, p.75 and Davidson 2005, p.616).

Although these examples place an emphasis on virtuosity, the one-handed repertoire can be utilised by any composer and performer with an interest in classical piano playing. More specifically, this repertoire could be advantageous for any pianist who is experiencing any form of pain because these injuries can be alleviated through recovery. The notation and techniques could be extrapolated for other pianists who play outside the field of classical music or even be examined and applied to other musical instruments. The piano and keyboard as instruments are open to many different techniques meaning that the piano can be played with two, one or no hands. Lubet (2004 and 2015) argues against the usefulness of the one-handed piano repertoire because the musician will not use their impaired hand; whereas, in jazz, musicians with impaired hands have used them in effective ways. To counter this, if more can be achieved through one-handedness to compensate sonically, then surely this is viable when compared to making long and arduous efforts to attempt to play with impaired hands. This means that it does not interfere with able-bodied pianists in any way. In fact, able-bodied pianists could try to use techniques and notation from the one-handed piano repertoire in their own playing, if they need or desire to (Lubet 2004, p.135, p.147 and Kral 1972, n.pag., see Dokumaci 2023, p.5 and p.7).

Key exponents of the classical one-handed piano repertoire are: Count Géza Zichy who lost his right arm in a hunting accident and was a renowned pianist of over 200 works, with

many piano arrangements for the left hand; Paul Wittgenstein whose right arm was shattered by a sniper's bullet and tirelessly exercised his left hand to make a triumphant return to Vienna in 1916, playing his one-handed recital; and Ravel who was adamant that in producing one of his most important works 'Concerto for the Left Hand': 'the listener must never feel that more could have been accomplished with two hands. The piano part must be complete, beautiful and transparent' (Drozdov et al 2008, p.784-785). This mirrors the quotation by the disabled sportsperson expressing their completeness without prosthetics (Manderson and Peake 2005, p.239). Even in the modern day, Nicholas McCarthy, who was born without his right hand, has played part of the one-handed piano repertoire, Ravel's 'Piano Concerto in D Major for the Left Hand' in the performance of Concerto (2016) (Pinchbeck 2016, p.2). Many of Wittgenstein's commissions are still performed today by two-handed pianists. This may be in part because of the fact that some of the techniques he innovated for the left hand such as '4/3' indicating the third and fourth fingers should play a note simultaneously and 'o' indicating certain passages are to be played with a fist (Drozdov et al 2008, p.785).

In a similar vein to the one-handed piano repertoire being associated with WW1 amputees, late 19th century and early 20th century southern roots music has an association with the American Civil War (Buck 2023, n.pag.). Another example of regaining wholeness is amputees losing limbs in the Civil War, yet feeling complete due to being able to play a musical instrument in an adapted fashion: 'the South had lost, in quite a literal sense, but could still be made 'whole' again' (Ibid.). This 'wholeness' may also be associated with the lack of income associated with late 19th and early 20th century Southern USA, hence why many amputees used cheap, DIY, makeshift solutions to play a musical instrument in order to earn a living such as busking, playing on the radio, and taking part in fiddlers' contests (Ibid.). Referring to everyday application, Dokumaci (2023) proposes that there should be 'disability repertoires', being a 'set of everyday survival techniques that disabled people create within the very constraints and normative environments that are imposed on them... how to go about reinventing like everyday in the face of restraints, failures, and losses' (p.27). A potential 'recipe book' (Ibid.) of adaptive music-making would be appliable for 'musical affordances' such as the one-handed piano repertoire for classical pianists with LDA. This collection could conceivably be added to if shared widely, especially across a

genre. Although many genres of music do not specifically have a repertoire for adaptive music-making, a repertoire of techniques, devices, and instruments has a potentially global reach.

It is not just instruments and notation which can be altered for a musician with LDA. Fellow musicians within their ensemble can compensate for, or enhance, their playing. As introduced earlier, an example of a musician who had to adapt his technique according to his impairment was jazz pianist Oscar Peterson. Peterson had a stroke in 1993 and returned to performing and recording again a year later. In an interview, Peterson explained that he did not have the same dexterity he once possessed. If he was to play a created musical phrase, he was more conscious before playing it and if it became too much, he would not attempt it. This is not to say that Peterson was not inventive in turning his technical limitations into an interesting and creative musical aesthetic (Lubet 2013 p.151 and p.153). Peterson decided to use his bandmates to compensate for the missing function of the majority of his impaired left hand. This allowed Peterson to change his style of playing to suit his needs. Therefore, the entire ensemble would adapt accordingly to create a unique style. These decisions were based on understanding how Peterson's technique had changed in order to optimise the band's compensatory musicality. This is predicated on careful arrangement of the instrumentation and using musicians with similar musical philosophies (Ibid., p.153-156 and p.163-164). The band acted as Peterson's functional instrumental prosthesis.

Peterson arguably used a popular musician on his first album post-stroke in order to gain acceptance from the audience. The musician in question was Itzhak Perlman. It had been suggested that the two musicians had planned to work together for a long time; however, the timing of this collaboration is of interest (Ibid., p.175). In terms of changing stylistically and musically, another insightful example is Jean 'Django' Reinhardt. Reinhardt had a musically-altering accident where his third and fourth fingers became paralysed on his fretting hand due to a caravan fire. Before his accident, Reinhardt played in ensembles with the banjo-guitar. However, afterwards, all of Reinhardt's recordings used the guitar. Patrick Williams, who was Reinhardt's biographer, suggests that this transition was due to the fact that, during recovery, the guitar required less force than the banjo-guitar to depress the

strings. This would suit Reinhardt's impaired fingers in order to have enough strength to play on the fretboard (Givan 2003, p.21-22). Both the examples of Peterson and Reinhardt, validate Garland-Thomson's point of view of 'reimagin[ing] disability' (2005a, p.523). Although Peterson and Reinhardt are not musicians with LDA, their adaptability is applicable to LDA musicality, which assists their playing in any form, be it: colleagues, repertoire, assistive devices, technique, or universally accessible instrumentation. I will need to examine the potential array of approaches for musical prosthesis for musicians with LDA.

1.3 Organisations supporting disabled musicians

Numerous popular musicians acquire their musical and instrumental skills informally and unconsciously, and even away from teaching altogether, such as being self-taught (Green 2002, p.5, p.55-56, p.59-60, and p.133, and Lebler and Hodges 2017, n.pag). Examples include: learning from other bandmates and through peers; composing, listening, playing, and copying; the involvement of parents; and learning from books (Green 2002, p.5, p.22-26, p.35-36, p.41-44, p.64, p.68-69, p.75-76, p.82-83, and Lebler and Hodges 2017, n.pag). This highlights how all music learning is individualised, with no two people having exactly the same experience of playing and learning music. However, LDA music-making usually needs more concentrated and dedicated provisions in order for musicians with LDA to learn and play music.

In order to assist disabled musicians learning in school settings, educators of adaptive and inclusive music education have tried to incorporate the use of certain parts of the law, especially noteworthy in the United States, such as: The Every Student Succeeds Act (ESSA); The Individuals with Disabilities Education Act (IDEA); and the Individual Education Plan (IEP), for the betterment of students with disabilities in the music classroom (Abramo 2012, p.40, p.42, Scott et al. 2007, p.38-39, Lubet 2011a, p.64, p.67, Lubet 2009b, p.728-729, Darrow 2016, p.41-44, Hammel and Hourigan 2011, p.174, and Jones 2015, p.13-14). Certain scholars have suggested that it is paramount for teachers to collaborate with a variety of specialists within and outside the school system, which the IEP can assist (Hammel and Hourigan 2011, p.174, and Jones 2015, p.13-15). There are issues with a child's IEP, as some

teachers are unaware of their very existence; how to plan their lessons incorporating the IEP; how to access the documentation or how to attend the meetings; and being generally uninvolved in the process (Jones 2015, p.15-16, Scott et al. 2007, p.42, 48-49). Several scholars have expressed the need for a better understanding of the IEP and inclusive education, as well as the demand for ongoing communication and collaboration with different specialists such as special educators, paraeducators, occupational and physical (music) therapists, as well as parents (Darrow 2003, p.46-47, Jones 2015, p.16-18, McCord and Fitzgerald 2006, n.pag, Hammel and Hourigan 2011, p.175-177, Montgomery and Martinson 2006, n.pag, Scott et al. 2007, p.46, p.48-50, p.53-54, Laes and Westerlund 2018, n.pag, and Green 2002, p.24-25).

It may be surprising that therapists should be involved in this process, especially with several disability studies scholars frowning upon the medical model of disability, which means that the focus is on the individual rather than the barriers imposed by society (Kielhofner 2005, p.487, p.489-490, and Lubet 2019, p.310-312). However, as Montgomery and Martinson (2006) state regarding music therapists: 'They [therapists] may also serve as consultants to teachers of students with special needs by providing information about specific disabilities and suggesting adaptations for lessons plans... Because most school systems do not have music therapists on staff' (n.pag). Through anecdotal experiences, Lubet (2019) has said that the use of physical therapy aided him in his personal life, as well as in his music-making (p.310-313). Although these measures may be useful, it may prove difficult to implement due to the process being time-consuming and expensive (Abramo 2012, p.39). There are further issues with inclusive music teaching such as the difficulty of adapting the curriculum in a way to facilitate the teaching of disabled students, particularly with the range of disabilities that may need to be adapted for, and potentially, music as a subject being cut entirely (Darrow 2003, p.45-47, Lubet 2009b, p.732-738, and Lubet 2011a, p.64).

Regarding occupational and physical (music) therapists, their value extends beyond collaboration with disabled students for therapy and performance for musicians with LDA. This includes: phantom pain relief; completeness; and strength for playing a musical instrument (MacRae 1992, p.275-276, Bailey 1986, p.25-27, de Jong et al. 2021, p.375,

p.377, p.382, Paul and Ramsey 2000, p.111-112, Craig 2008, p.80, p.82-84, Woldendorp and van Gils 2012, p.231-232, and Lubet 2019, p.313). With the individualised music-making of musicians with LDA, multidisciplinary collaboration and communication between occupational and physical therapy and other fields is required (Kielhofner 2005, p.491-493, Bailey 1986, p.27, Paul and Ramsey 2000, p.112-117, and Woldendorp and van Gils 2012, p.236). Disability scholars have taken a dim view of occupational therapy (Lubet 2019, p.310-311). Some of the criticism involves: the need for appraisal by a professional; the focus being on the individual, instead of environmental factors; and the goals of the therapist not being musical, whereas, the goals of the musician are for improved musical instrument proficiency (Kielhofner 2005, p.487, p.489-490, and Lubet 2019, p.312). Lubet (2019) provides the example of an organisation, which tailors instruments and builds devices, particularly for one-handed musicianship, being the Centre for Rehabilitation and Music in the Netherlands (p.313 and p.320). Lubet (2019) explains that the favoured social model of disability can be benefited by the much-maligned medical model of disability: 'The work of the Centre is affirmation of the value of medical praxis to disabled musicking as well as an admirably holistic view of medicine that values the arts as fundamental to quality of life' (p.313, see Abramo 2012, p.40, Lubet 2009a, p.124, Paul and Ramsey 2000, p.111, Craig 2008, p.73, p.76-77, and Woldendorp and van Gils 2012, p.231).

Collaboration between disabled musicians and the practitioners assisting them is of great importance. With the 'Music AccessAbility' hackathon in New York City, not a single one of the designers was disabled and the designers did not 'collaborate with the very people for whom they were designing' (Bell et al. 2020, n.pag). Although the need for disabled music-making is being addressed, it is sometimes being addressed in an ill-guided manner. The mentality runs counter to the mantra of the Disability Rights Movement: 'Nothing about us without us'. Samuels (2019) reports that when Drake Music Project Northern Ireland builds and modifies accessible musical instruments and technology for collaboration, this process should be open-source, flexible, adaptable, and tailored to the individual needs of the musician, as well as needing the specific knowledge of certain practitioners in order for the continual adapting of an instrument (p.152 and p.159). Some manufacturers and musicians are seeking instruments which are specifically tailored to certain impairments. The One-Handed Musical Instrument (OHMI) Trust through unorthodox accommodated instruments,

can showcase the contrasting bodies of one-handed musicians through unique presentation of their instrumental proficiency. This, in turn, nullifies the differences between one-handed musicians and able-bodied musicians sonically (Howe 2016, p.199-200).

Beyond instrument design, OHMI, as an organisation, has recognised that the entirety of the teaching process could be enhanced through improved adapted musical instruments and devices for specific needs, provisions, expertise, resources, and greater communication and collaboration with local organisations and practitioners. Two reports produced for OHMI and written and published at Birmingham City University (Independent Evaluation of the OHMI Teaching Pilot 2017 and OHMI Music Makers Report 2018) have provided extensive information on the processes undertaken with a view to improving the experience of disabled children learning to play a musical instrument and all collaborators involved in the future (Fautley and Kinsella 2017, and Kinsella and Fautley 2018). Another localised collaboration is the Cincinnati Adaptive Music Camp. Co-founder Deborah Amend (2014) explains that the camp was formed by herself and another parent of children with 'limb differences', in collaboration with the not-for-profit organisation, May We Help, which built adapted devices for the musicians (p.20). This process involved collaborators throughout with a plan (similar to other adapted teaching plans) called the Music Adaptation Plan (MAP) teamed with a local private lesson teacher. From an occupational and physical therapy perspective, the plan is also guided by video and photo supplements of 'proper hand and body position', as well as the May We Help volunteer engineers providing free ongoing consultations with local private teachers in order for the Music Adaptation Plan to be rewritten based on evaluation (Ibid.). Professor of Music and adapted toggle-key saxophonist who plays right-hand only due to having a stroke, David Nabb, visited the camp (Nabb 2017). Nabb (2017) explains the value of the camp for improving LDA musicality through the local partnership of the Cincinnati Adaptive Music Camp and May We Help: a model which could be used more widely (Ibid., p.22-24).

Based on my conclusions of the important topics uncovered in the scholarship surrounding LDA musicality, I have devised three research questions:

1) In what ways have famous musicians with LDA been represented in visual and biographical forms of media including: documentaries; news segments; television

- programmes; artwork; publicity photos; merchandise; music videos; and music performances?
- 2) In what ways are prostheses; technology; musical devices; instrumental modifications; and technique important to musicians with LDA in relation to their musical and performative aims?
- 3) What level of organisational and institutional support is there available for musicians with LDA and what are the potential implications of this support or lack thereof?

Chapter 2 – Methodology

Based on the establishment of three research questions, I needed to address how and why these questions would be examined through the methods I adopted. The literature review for studying musicians with LDA has informed the choice of research methodologies and research questions to be implemented as a cohesive through-line for this thesis (see Galletta 2013, p.15). The research questions and the use of methods were strictly interwoven (Ibid., p.21). The research methodology involved the use of a mixed-method approach across the thesis. The rationale for this mixed-method approach is that I studied various stakeholders across LDA musicality such as: musicians with LDA, music teachers, instrument and device makers and designers, prosthetists, organisations, music education hubs, and even relevant medical professionals such as occupational and physical therapists, surgeons, and physicians. This chapter provides details on each method adopted, how these methods were adopted, and the rationale for their use in this research. The methods involved were textual analysis, case studies, thematic analysis, semi-structured interviews, and to a lesser degree, surveys.

As the study of media and LDA representation is formed by a plethora of visual and audio stimuli, textual analysis has been utilised. These stimuli are categorised as texts based on McKee's (2003) definition:

If textual analysis involves analysing texts, then – what exactly is a text? Answer: whenever we produce an *interpretation* of something's *meaning* – a book, television programme, film, magazine, T-shirt or kilt, piece of furniture or ornament – we treat it as a text. A text is something that we make meaning from (p.10).

McKee (2003) defines the action of textual analysis: 'When we perform textual analysis on a text, we make an educated guess at some of the most likely interpretations of texts made by people who consume them' (Ibid., p.8). With regards to visual media, I used textual analysis which consisted of artwork, merchandise, music videos, concert performances, publicity photos, and relevant visual biographical accounts such as documentaries, news

segments, and television programmes. The media representation of these sources was determined by different people such as the musician themselves, fellow band members, collaborators, and media professionals. It was important to investigate how musicians with LDA control how they are represented or if it is dictated by others and if this position changes depending on the use of a certain text. The established themes of the overcoming and supercrip narratives, along with passing, reverse passing, and masquerading were prevalent within the textual analysis. For instance, as documentaries, news segments, and television programmes are produced and directed by public channels, the overcoming and supercrip narrative may be unavoidable, particularly for a musician with adventitious LDA who may have had to 'overcome' an accident in order to return to being a public figure and performing musician. Textual analysis of visual media was also applied to prosthetics as visual imagery provides a platform for showcasing prosthetics. It was illuminating to contrast the imagery of prosthetics with the absence of LDA and the similarities and differences between these types of imagery.

The rationale for choosing music videos, music performances, merchandise, artwork, and publicity photos was that these visual stimuli facilitated an understanding of how famous musicians with LDA have navigated several representational aspects of being a public figure. For example, determining whether passing, reverse passing, or masquerading have been adopted for certain visual stimuli and whether there are similarities and differences between various visual media. This was important because I needed to understand what the musician, or media professionals, were aiming to achieve by using a certain type of media to highlight or hide impairment, and the implications of these decisions. Music videos and music performances provided another visual perspective of the musician with LDA in a nonstatic, performative setting, which provided both representations of LDA such as passing and masquerading, and representations in performance being how LDA is connected or bypassed musically. In contrast, artwork, merchandise, and publicity photos provided a viewpoint of a musician with LDA from a static, non-performative perspective. Furthermore, the inclusion of the representation of prosthetics and instrumental prosthesis (see Lubet 2013) incorporated both aesthetic and functional concerns. Examples include presenting prosthetics in contrast to the absence in the body visually, and the methods, devices, and techniques applied to negotiate prosthetics in order to play a musical instrument.

Although I explored these visual media across the career of musicians with LDA, I needed to be selective in the resources I chose to explore in detail. The texts chosen needed to clearly display the musician with LDA presenting or being presented through the themes established in a manner, which was clear. The introduction of (auto)biographical information on these musicians included: their personality and how they approach playing their musical instrument (or navigate their prosthesis and limb absence); the genre they operate in and the band or group they play in; and the accounts of other influential people or collaborators in these musicians' lives. Aspects which were important for understanding how and why certain methods have been adopted across different visual texts. The four famous musicians with LDA investigated in chapter 3 were: Black Sabbath and heavy metal guitarist with two-partially absent digits on his fretting hand, Tony Iommi; The Grateful Dead and psychedelic rock singer and lead guitarist with a partially-absent finger on his strumming hand, Jerry Garcia; Def Leppard and glam metal drummer with an absent left arm, Rick Allen; and pop singer with a below-the-knee absent left leg and 'bionic pop artist', Viktoria Modesta. The reason these musicians with LDA were chosen is that they are highly recognisable as being a musician with LDA and/or for their mainstream exposure as a popular musician. For example, before this study, I knew that Jerry Garcia was the guitarist and lead singer of The Grateful Dead yet did not know that he had LDA. Although three of the musicians work within the genre of rock, they operate in various sub-genres, have numerous approaches to music-making, and differing forms of LDA. In addition, the introduction of Viktoria Modesta shifted the focus in an entirely different direction to an alternative musical genre, presentation of LDA and prosthetics, and approach as a popsinger rather than an instrumentalist.

These famous musicians with LDA have been investigated as case studies. Yin (2009) postulates when the case study method should be used:

The more that your [research] questions seek to explain some present circumstance (e.g. "how" or "why" some social phenomenon works), the more that the case study method will be relevant. The method also is relevant the more that your questions require an extensive and "in-depth" description of some social phenomenon (p.4).

This case study approach allowed for thorough analysis and provided meaningful observations (see Gerring 2004, p.348 and p.353). As I discussed the meaning of, and rationale for, adopting visual media and foregrounding or backgrounding LDA depending on each media, the chosen method was appropriate. The case study approach transitioned naturally to the thematic analysis with the media representation chapter. This development is in keeping with the definition of a case study being: 'an in-depth study of a single unit (a relatively bounded phenomenon) where the scholar's aim is to elucidate features of a larger class of familiar phenomena' (Ibid., p.341). The thematic analysis adopted provided a wealth of information and although commonalities were found, Gerring (2004) states: 'When one is examining correlative relationships or proximate causal relationships the case study format seems less problematic and is often highly informative' (Ibid., p.347). Nowell et al (2017) explain that the advantages of thematic analysis are that the method is flexible, modifiable, accessible, graspable, helps highlight 'similarities and differences', and 'generate unanticipated insights' (n.pag). Chapter 4 explored a variety of lesser-known, grassroots musicians and their approaches to LDA musicality ranging from adapting to an instrument, using an adaptive device for stability or playing, and wholesale instrument redesigns. These aforementioned themes provided a framework for the structure of the chapter with the experiences of certain musicians with LDA forming the content of the chapter.

Chapter 5 examined four specific music and disability organisations which assist musicians with LDA. Not only can individuals be explored for case studies, organisations are applicable too: '[a]s a research method, the case study is used in many situations to contribute to our knowledge of individual, group, organizational, social, political, and related phenomena' (Yin 2009, p.4). This involved the organisation's remit, mission statement, ethos, infrastructure, operations, practices, personnel and employees, funding, and most significant collaborations and projects. This again was a hybrid of the case study approach and thematic analysis. The utilisation of thematic analysis has allowed me to provide a structure for this thesis by balancing the scholarship from the literature review (which has been guided by research), and the investigation of musicians with LDA and organisations assisting them (which has been guided by the interviewees and survey respondents' input).

I interviewed ten people for this study; six musicians with LDA and four key individuals working for organisations which assist musicians with LDA. After careful deliberation, I found that this sample size provided a balance for producing a wealth of information, yet was not excessive. There were three interview methods to choose from: unstructured, semi-structured, and structured. I determined that semi-structured interviews were the best option. Galletta (2013) expounds the virtues of semi-structured interviews:

The semi-structured interview provides a repertoire of possibilities. It is sufficiently structured to address specific topics related to the phenomenon of study, while leaving space for participants to offer new meanings to the study focus... the arrangement of questions may be structured to yield considerable and often multidimensional streams of data... A key benefit of the semi-structured interview is its attention to lived experience while also addressing theoretically driven variables of interest (p.24).

Furthermore, I postulate that semi-structured interviews provided the perfect balance between unstructured interviews, which would not have allowed me to obtain enough salient information on my interviewees, and structured interviews, which would not have given the interviewees space to deviate from more inflexible questions at appropriate junctures.

The questions were tailored to the individual musician with LDA or the representative of music and disability organisations to facilitate extensive research on said parties beforehand. I was able to gain a greater insight into the interviewees' experiences and personal thoughts on important individual and institutional aspects of LDA musicality rather than being limited by questions, which did not give the interviewee the freedom to express their views. The six musicians with LDA chosen for this study were: one-handed jazz saxophonist, Neill Duncan; reggae fusion but more recognisable as a 'cyborg' drummer with an absent forearm who utilises a prosthetic drumstick, Jason Barnes; folk and rock guitarist and singer-songwriter with an absent forearm who utilises Gorilla tape to hold a guitar plectrum to his forearm, Tony Memmel; a rock guitarist who plays with a prosthetic plectrum holder on his absent forearm, Jason 'Lefty' Williams; armless classical, pop, and

rock multi-instrumentalist who plays with his feet, George Dennehy; and an adaptive classical pianist born with an atypical cleft hand (with two fully-formed digits on the right hand) and founder of the website for sharing teaching methods and adaptive prosthetic devices for LDA, 'Another Way to Play' (Thomforde 2021 and Lubet 2019, p.317), Valerie Thomforde.

The reason I selected these six musicians with LDA is that they cover a wide-array of: musical genres, types of LDA, musical instruments, methods of music-making, and building or modifying devices and their instruments. I did have a shortlist of approximately twenty musicians with LDA that I was contemplating contacting. With the interviewing method, availability would always be an issue for which interviewees would be chosen. For example, I had several UK-based musicians with LDA on my shortlist who either did not respond to my initial request or would not have provided comprehensive enough responses to my interview questions. However, I am delighted with the variety of participants I was able to interview. The nature of the questions involved their approaches to playing their musical instruments, which involved support from organisations, institutions, or specific pragmatic individuals; the processes they went through for building an instrument or prosthetic device; and issues surrounding LDA musicality based on their own experiences. It is worth noting that Thomforde and Dennehy are classically trained even though my focus was on popular musicians. This classical bias (see Lubet 2019, p.317-320) became a prevalent commonality to emerge from this research. However, both Dennehy and Thomforde's work has great value in popular music. Dennehy did transition his classical training on the cello to popular genres with the bass guitar, acoustic guitar, and piano. Furthermore, although Thomforde is a classical pianist working in that field, her work translates to popular music with her interest in adaptive music-making through adapting and adaptive devices such as through her website, 'Another Way to Play' (see Thomforde 2021).

This rationale is supported by Galletta (2013) postulating that when choosing interviewees, questions need to be asked including: '[w]hat individuals are most likely to offer responses relevant to your research question? Where might there be gaps in locating diverse perspectives and experiences as it relates to your research question? How will you fill in those gaps?' (p.33). To supplement this interview data, other lesser-known, professional

musicians with LDA and disabled musicians studied by scholars or with significant information on them, which can have commonalities with another experience of a musician with LDA were introduced in chapter 4. This data was used in order to understand the thought processes of using certain methods, equipment, and techniques for playing. This information strengthened the interview data gathered in this chapter. Buck (2023) emphasises the need for information on lesser-known musicians with LDA, such as the majority of southern roots musicians who were known by a small number of people, to be shared for the sake of historical prosperity (n.pag.).

To complement the six musicians with LDA interviewed previously, four representatives of music and disability organisations were chosen for interviews and the organisations were individual case studies. The four organisations chosen were: The One-Handed Musical Instrument (OHMI) Trust; Drake Music; May We Help and their collaboration with the Cincinnati Adaptive Music Camp; and Can-Do Musos. The main reason that these organisations were chosen was because they provide various provisions, resources, equipment, and expertise, which have helped, and could help, musicians with LDA for teaching, playing, and making solutions in a multitude of ways. OHMI is an emerging UK organisation, which is the most closely related to the area of LDA musicality: one-handedness (and beyond) (OHMI 2016a). In addition, the OHMI conference in 2018 is the only conference (I am aware of) which has brought together LDA practitioners in one place (OHMI 2022a). Drake Music is well-established as one of the leading music and disability organisations in the UK. Drake Music is responsible for various nationwide projects and collaborations involving the accessibility of music technology and instrument design (Drake Music 2017b).

With the May We Help and Cincinnati Adaptive Music Camp collaboration, CAMC did not have the resources, provisions, and equipment of an organisation for assisting musicians with LDA. However, they did have the expertise in teaching various musicians with LDA (Bonis 2016 and May We Help 2020c). Can-Do Musos is an organisation with a global reach for assisting disabled musicians by providing funding which allows these musicians to network and collaborate with practitioners in professional settings (Can-Do Musos 2017e). I chose to interview one of the senior figures in each of these organisations being: the co-

founder of the One-Handed Musical Instrument (OHMI) Trust, Dr Stephen Hetherington; the (now) former CEO of Drake Music, Carien Meijer; the co-founder of the Cincinnati Adaptive Music Camp (CAMC) and teacher of various musicians with LDA, Jennifer Petry; and one of the four co-founders of Can-Do Musos, David Segal. I asked these interviewees about their organisations based on their remit, operations, infrastructure, funding, and most significant projects. I elaborated on how the organisations were able to help musicians with LDA for their various LDA musicality needs such as with teaching, playing, and making. Finally, I discussed some of the issues surrounding LDA musicality provisions such as connectivity and sharing, which can be due to the nature of these organisations being under-resourced and under-funded.

To understand the scope of collaboration between organisations and music educational services, I surveyed a couple of UK-based music education hubs in school settings in particular. I allowed the survey respondents to provide their answers in the body of the email thread (see Schonlau et al. 2002, p.1). The reason I surveyed music education hub representatives was I needed to understand the hubs in broader terms regarding their infrastructure, projects undertaken with disabled musicians, and how the hubs would be able to help a musician with LDA. The reason I did not interview these senior representatives is the questions created for an interview would not be suitable for a person representing a music education hub to answer, because they do not have the same perspective as musicians with LDA and organisations which assist them.

In order to determine which music education hubs were chosen, I found a directory of all music education hubs on the website of, the leading Music Education Membership organisation, Music Mark (Music Mark 2022). To avoid geographical bias, I used a random number generator and then, numbered the hubs in order from 1-146 and drew a number to determine which music education hub I would approach. I contacted over a dozen UK music education hubs requesting information for my survey and representatives from only three music education hubs completed the entire survey process. I decided that having information from two to three music education hubs would be sufficient because the practitioners who replied were clearly interested in improving the assistance of musicians with LDA. The two named individuals from UK music education hubs are Yogesh Dattani,

Head of Ealing Music Service (Ealing Music Service 2023a), and Tom Deam, Music Development Lead for Teignbridge & Torbay (Devon and Torbay Music Education Hubs 2023).

Regarding the process for interviews and surveys, I offered all my respondents anonymity. All but one of the participants agreed to be named or in the case of music education hubs for their hubs to be named in this thesis. The third music education hub respondent did not want to be named, which I shall respect (hence why I did not include their name and signature in their specific consent form and redacted specific information from their responses, see Appendices 3 and 16). Furthermore, as the third person's perspective was far removed from the area of LDA musicality, I have not used their responses in this thesis. This is not to say I do not appreciate their response: this lack of clarity highlights a greater issue that I was passed on to a practitioner whose expertise is not strictly relevant for the practicalities of LDA musicality.

Regarding anonymity for the musicians with LDA and the key individuals from organisations assisting them I interviewed, I explained that due to their public profile, anonymity may prove difficult. Two interviews were conducted in person during my attendance at the 2018 OHMI conference, with a third interview organised at the conference and conducted later as a recorded telephone interview. Six more interviews were conducted as recorded telephone interviews, and the final interview was recorded over Zoom (see Galletta 2013, p.22). I gave all interviewees the option to choose whichever method they desired in order to conduct the interview. Throughout the interview process, I was transparent starting with providing a participant information sheet detailing the study and my position as a researcher together with a consent form, which stated their agreement to be part of this study (see Appendices 2 and 3). In each case, this consent form was completed by the interviewee or survey responder before I carried out the interview or transcribed the responses from the surveys (see Appendix 3). Finally, towards the end of the process, I sent all statements taken from the transcripts for the approval of each interviewee and survey responder. I gave the respondents one month to read their relevant excerpts from the thesis, which needed to be approved, amended, or omitted (with no reason required by the interviewee or respondent). If I did not receive a response, I kept the excerpts unchanged because I had

written consent. I did this because I wanted to be fully transparent and to provide the respondents with an opportunity to read through and check their responses.

All of these criteria were followed and adhered to as per my research ethics approval (see Appendix 1). Before any interview or survey was conducted, the research received ethics approval from The General Research Ethics Committee (G-REC) of the University of East Anglia. This fact was conveyed to all interviewees and survey respondents during my initial contact with them. The criteria involved: answering yes or no questions regarding the nature of the research; my intentions for the research and the protocol I would follow throughout the research project; sending a participant information sheet to the interviewee or respondent stating who I am as a researcher, an overview of the project and why I am conducting the study, and what I hoped would or could be gained from this research; and sending a consent form to be signed and completed by each interviewee and respondent. Furthermore, I explained that only myself, my supervisors, appropriate in-house departments, and relevant participants (a participant could only access their own data) would have access to interview transcripts and excerpts during the process. Finally, for best results and security, I recorded all interviews through two Dictaphones (a primary and a back-up) and all data would be encrypted and stored on a personal computer and personal USBs, only I would have access to.

In summary, with the wealth of rich material, which surrounds being and assisting a musician with LDA, it is understandable why I have adopted a mixed-method approach to the thesis. The research through-line transitions smoothly from one chapter to the next with signposting throughout, starting in chapter 3 with media representation which involves the cultural context and popular music perspective of famous musicians with LDA. This shifts to an individualistic approach with lesser-known, grassroots musicians and themes based on the various approaches to LDA musicality in chapter 4. This moves towards the organisational approach through the case study method of prominent organisations assisting musicians with LDA, and the potential scope of UK music education hubs supporting musicians with LDA in chapter 5. In the conclusion, previous data has been collated in order to understand whether LDA musicality is defined by tensions between the individualistic and organisational aspects and contrasting complementary factors therein.

Finally, the notion of advocacy across LDA musicality is a natural extension of the subject area and has been applied to discover where research gaps in this complex area can potentially be filled in.

Chapter 3 – Biography, (Auto)pathography and Representation in Four Prominent Popular Musicians with LDA

When I woke up from my operation, opening up the covers and not seeing anything there at all – it was like Christmas.

LDA pop singer Viktoria Modesta (quoted in Channel 4 2014)

'Ah well, what's this? Drugs?' And then, shock, it's fingers. I've had to explain it to customs on several occasions.

Black Sabbath LDA guitarist Tony Iommi (Iommi 2012, p.23)

This chapter introduces the four key case studies of musicians with LDA, and seeks to weave together elements of both biography and pathography, that is personal and musical history and medical condition. It also, since popular music is a hugely mediated form, introduces and explores important questions of the media representation of disability. Due to the nature of LDA as a subject area, impairment varies from the seemingly slightest forms such as a partially-absent digit or fully absent digit(s) to the most noticeable forms of LDA being partially, and fully, absent limb(s). This can be compared to Lubet's (2011b) investigation of how the slightest physical forms of LDA can have a far greater musical impact on a musician's individual technique versus the obvious physical forms of LDA (p.43-51). Therefore, exploring the negotiations of popular musicians with LDA in music and media settings will be illuminating as to how the nature of LDA factors into media representation. Furthermore, the media representation regarding musicians with LDA has not been explored in great detail, which provides this gap in research (although see McDermott 2022). Despite expectations, a musician with a slight form of LDA may have their impairment accentuated and exaggerated in different media forms. Conversely, a musician with more visually noticeable forms of LDA may have their impairment diminished or hidden, although this may prove more difficult. Additionally, the introduction of prosthetics further complicates LDA music and media representations as it creates a new visual element. The use of realistic (aesthetically speaking) prosthetics may be a form of normalisation as a method, which can cover up or obscure LDA and not distract audiences.

By contrast, a musician with LDA may use a prosthetic which is non-anatomic by design. This has been popularised across the Paralympics and can move beyond the human expectations of limbs and digits (mostly limbs) to futuristic, utopian LDA incorporating elements of prosthetics with science-fiction and popular culture (see Braidotti 2013, p.3 and Haraway 1991, p.163-164). The showcase or normalisation of LDA in different media forms can be unique in its nature due to the fact that highlighting the absence of a limb or digit can be visually striking and can capture the attention and 'stare' of the viewer, before even being associated with music. The absence becomes a narrative device when viewed, as the public want to understand more: 'staring is an interrogative gesture that asks what's going on and demands the story' (Garland-Thomson 2009, p.3). By contrast, the conscious effort to hide LDA may also be used to background LDA to shift the focus onto music solely. This is not to say that musicians with LDA or others around them are always thinking about their LDA and its visual effect on audiences. However, the representational strategies adopted are of interest.

To unpack the complexities of LDA media representation, the first research question will be addressed: 'In what ways have famous musicians with LDA been represented in visual and biographical forms of media including: documentaries; news segments; television programmes; artwork; publicity photos; merchandise; music videos; and music performances?' A case studies approach will be the method used. A detailed investigation into a small sample size of musicians with LDA is more illuminating than investigating a large number of musicians, which may not allow for an in-depth analysis of different biographic, pathographic, and representational material. At the same time, if this chapter were structured around the individual representational forms, this would not be focused enough as the musicians with LDA in this chapter have been represented in various ways. I believe a case studies approach using four key themes across the chapter as a common thread will be a suitable method. Then, in the concluding discussion, these themes can be drawn together for all four case studies. If the main themes were investigated through the examination of different media forms, this would be unwieldy and harder to synthesise in a coherent analysis and conclusion. Themes can be explored relating to the individual as different musicians play and use distinct instrumental idioms and techniques in various music genres,

a factor of representation. This will allow for an investigation into individual relationships of musicians and their LDA in personal, musical, and medical terms.

The case studies for this chapter have been chosen as they are probably the most well-known and recognisable musicians with LDA in popular music in terms of audiences reached and impact on popular culture. The four musicians have differing LDA: two with partially-absent fingers (one with two absent fingertips and one to the first joint of the middle finger) and two with absent limbs (one partial and one full). The four musicians have different roles in their respective band/solo projects—a solo singer, a guitarist and singer, a guitarist, and a drummer. Although three of the case studies are rock musicians, they operate in different sub-genres—heavy metal, glam metal/rock, and psychedelic rock (and folk rock to a lesser degree), with the other being a pop musician. The foregrounding and backgrounding of LDA varies greatly across the four musicians with one focusing on foregrounding their LDA and the others frequently backgrounding LDA, with differing approaches to foregrounding in different media settings. The four case studies will provide a mixture of detailed individual analysis, relating the case studies to one another and drawing the four key themes together in a concluding discussion.

The first case study will be Tony Iommi, one of the founders of heavy metal as a genre of music. Iommi's band, Black Sabbath, encapsulated the dark, gothic, occult aesthetic of heavy metal through their choice of clothing, lyrical content, and, of course, the music being a key factor in Sabbath's presentation. The driving force behind this is the guitar sound of Tony Iommi, which has been well-documented. This was directly affected by Iommi losing the tips of his ring and middle fingers of his fretting hand (which, as a left-handed guitarist, was his right hand). This led to Iommi creating his own makeshift prosthetic fingers, as well as adapting his instrument through devices such as light gauge strings and filing down the frets (other significant adaptations will be discussed later). Conversely, how Iommi's LDA was presented across different media forms has not been explored in any great detail. As the story of Iommi's accident has become the lore of heavy metal origins, it will be illuminating to understand how LDA representation fits within this. The second case will be the late Jerry Garcia (1942-1995). Garcia was another famous rock musician in a different sub-genre of rock music, being psychedelic rock. Garcia was the lead guitarist and singer of

The Grateful Dead. Like Iommi, Garcia had what we might think of as slight LDA, with a partially-absent middle digit on his right hand. However, unlike Iommi, as Garcia was a right-handed guitarist, he did not have to make significant changes to the guitar or his partially-absent digit. It is intriguing to see how Garcia's LDA had only a slight effect on his music-making (only impacting his fingerpicking style for his guitar and banjo playing). Additionally, Garcia's LDA representation, while seemingly minor, is in fact visually-striking and important as a promotional tactic. Later in his career, Garcia used a variety of methods, which only grew posthumously through the intervention of those who had been close to him.

The third case study will be Rick Allen. Allen is a rock musician in another sub-genre—glam metal from the 1980s. Due to the fact that Allen lost his entire left arm in a car accident, and because this had such a profound impact on his drumming, this differs to Iommi and Garcia greatly in visual and performative terms. Arguably even more than Iommi, Allen had to make significant changes to his music-making, with the introduction of an electronic adapted drum kit incorporating more foot pedals controlled by his left foot as a direct replacement for his absent left arm. Rick Allen is also famous for being the one-armed drummer in popular music, shaping his music and media representation, which this chapter will explore in detail. The final case study will be Viktoria Modesta. Modesta contrasts with the other three case studies as she is a female contemporary musician with LDA in the pop genre. Additionally, Modesta is a solo artist who foregrounds her LDA centrally in her selfpresentation in music, media and promotional materials. Modesta has a partially-absent left leg and uses a variety of futuristic prosthetics for numerous media forms, which also function as fashion texts and statements. The most significant work, which incorporates Modesta's own personal history and her stance on disability issues, is captured in the music video Prototype (Farahmand 2014) for the single of the same name (Modesta 2014), which will be analysed in detail.

These four case studies differ greatly in how they have accommodated and represented their LDA and been depicted in various media. Therefore, to investigate commonalities and differences between them, four primary representational issues will be introduced and analysed to understand the bigger picture surrounding the media representation of musicians with LDA. These issues are: the context of musical genres such as the utilisation of

certain aesthetics and sounds; the foregrounding or backgrounding of LDA across different media forms; the nature of a musician's LDA and how this affects their representation; and the stage of a musician's life in which their limb or digit became absent and their level of openness about their LDA through their musical careers. The first theme will relate to how each individual musician's chosen genre affects their media representation. The conventions of musical genres will be explored to uncover the portrayal of a musician with LDA based on audience expectations, the flexibility of presentation within certain genres, and existing media representation. As LDA representation is rare across popular music, this will not be definitive. However, this issue will highlight the variety in line with how different genres operate. The next issue will be an investigation of each musician's LDA either being foregrounded and/or backgrounded in different media settings. This will link to musical genre, which may dictate the presentation of LDA. However, different factors affect how a musician with LDA or those around them would choose to highlight LDA or downplay, possibly hide, LDA depending on the context. These aspects of foregrounding may be applicable to other musicians with LDA or the factors may be based solely on an individual's own experiences.

The third issue refers to the nature of LDA and how this links to the two previous themes. The natural assumption would be that the more visually noticeable LDA is, the harder it will be to downplay and accept the foregrounding of this type of LDA is inevitable. However, slight LDA can be illuminated in different media settings in overt ways, which will be explored. The use of prosthetics will also affect the representation of LDA. The final issue involves the stage of life when the musician's status changed to 'a musician with LDA' and when in their career the musician referred to or displayed their LDA. Here is where (auto)pathography and representation merge. If a musician had LDA before they became a popular musician, they may choose not to engage with LDA representation in different media settings. If a musician had LDA during their popular music career, LDA media representation may be unavoidable. It is worth noting that there will be crossover between these four issues, depending on the context in which they are used. Such interconnectivity will be discussed.

3.1 'Fingers Bloody Fingers': Tony Iommi, the sound of heavy metal, and the rock guitar

This section starts by exploring the stage of lommi's career when he lost the tips of two of his fretting fingers to uncover how this affected his playing and the fabled nature of lommi's accident. Then, the effect that lommi's accident had on his playing technique and overall sound will be analysed. The rationale for this is that the pursuit of this new 'sound' directly influenced heavy metal as a genre of music and its importance cannot be overstated. This has expanded beyond the 'sound' of Black Sabbath to other factors such as their desolate home environment of Aston, Birmingham, the band name itself, and the overall occult aesthetic in the music, image, and lyrics, all contributing to the growth of heavy metal as a genre. Finally, aspects of lommi's personal representation will be of interest as it deviates from the 'power' of heavy metal to understating his LDA and its influence on his guitar playing. As a media source which encapsulates numerous themes surrounding lommi's accident and the origins of heavy metal, the Vh1 Classic animation entitled *Fingers Bloody Fingers* (2015), will be discussed throughout this section in conjunction with aspects of lommi's LDA representation.

Fingers Bloody Fingers (executively produced by Orlando Lima) is a 2015 animated segment from the heavy metal episodic talk show, *That Metal Show* airing on Vh1 Classic.² The three-minute thirty-six second animation provides a single entry for the wider discussion of the origins and progression of heavy metal as a genre. This is evident with the full title of the video being: 'The Complete History of Heavy Metal: Volume 1 Fingers Bloody Fingers' (Lima 2015). Although lommi was interviewed for *That Metal Show* back in 2011 (see Heydt 2011), the animation was created in 2015 based on a separate telephone interview (see Lima 2015). This segment is based on lommi's voice as a narrator of his own story from his childhood growing up in Birmingham; the details surrounding the day of his accident; the influence of Jean 'Django' Reinhardt (1910-1953) as a guitarist who had a similar impairment; and the methods lommi used to adapt the guitar to his specifications and create his own sound. Iommi giving a first-hand account is not uncommon in interviews,

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² This should not be confused with Iommi's appearance in a full episode in 2011 (see Heydt 2011).

however, the added visuals bring new life to his accident in a stylised, animated form, as the narrative is intriguing and bizarre for the average musician.

Tony lommi worked in a sheet metal factory in his hometown of Aston, Birmingham as a 17-year-old in 1965 (Iommi 2012, p.xii, p.20-21). Iommi was to quit this job and go to Germany as part of a European tour with one of his pre-Sabbath rock bands (Lima 2015 and McIver 2014, n.pag.). During Iommi's final day doing factory work, he was told that, for the first time, he was going to use a large machine which presses metal. Iommi went home to talk to his mother during his lunch break and told her that he was not going back in the afternoon. His mother persuaded him otherwise (Lima 2015). This addition to the story is obviously a storytelling device to introduce the hypothetical notion that if Iommi had not gone back to work, he would still have all his digits and would not have created heavy metal.

Figure 1 – The graphic image of the animated lommi with bloody fingers (Ibid.).

This image from the *Fingers Bloody Fingers* (2015) animation depicts the moment when lommi loses the ends of two of his digits. We see the animated version of lommi returning to work using this new machine, which he admits he was too inexperienced to use, and then *'BANG'* as the heavy metal of the machine crushes his fingers (1.20). As lommi pulls his

fingers from the industrial machine, we see a shot of lommi holding his hand with blood squirting out of his two partially-severed digits (1.24, see Figure 1). As this is an animation, the exaggerated fountain of blood has been used to emphasise the horror of such an accident. When building up to this moment, the imagery shows the metal being fed into the machine and several camera cuts to lommi's face. This intensifies with the metal cutting noises and quick cuts used (1.14-1.20) and when lommi says the word: 'BANG', it is reverberated with an echo, for further emphasis (1.20). These aural and visual devices give the viewer the sense that this was a devastating point for lommi in his personal story. This catastrophic event meant that his guitar playing was taken away from him by 'heavy metal'. The methods used by lommi to relearn the guitar after his accident show the viewer how the 'heavy metal' of the factory machine had influenced how lommi approached the guitar. As will become evident later, this moment was the 'death' of Tony lommi as a conventional rock guitarist. Thus, lommi was 'reborn' as a brand-new unique guitarist who, through his approach to the guitar and utilising the tools at his disposal, contributed to the 'birth' of the sub-genre, heavy metal.

When the metal crushed lommi's fingertips, the digits had to be amputated down to the first joint on the middle finger and most of the first joint of the ring finger (McIver 2014, n.pag.). Superficially, this may seem to be slight LDA, however, in terms of guitar playing, it had a significantly detrimental impact (see Lubet 2011b, p.43-51). In the Lima (2015) animation, Iommi's outlook on his accident is positive:

Of course, losing my fingertips was devastating but in hindsight, it created something. It made me invent a new sound and a different style of playing and a different sort of music. So, really it turned out to be a good thing off a bad thing (quoted in Lima 2015).

Elsewhere, Iommi has contested this by claiming:

It [losing my fingertips] became a burden. Some people say it helped me invent the kind of music I play, but I don't know whether it did. It's just something I've had to

learn to live with. It affects your playing style; you can't feel the strings, and there are certain chords I can't play (quoted in Elliott 2016).

This vacillation is context-dependent. In the Lima (2015) animation, Iommi's downturn is documented straight after his accident with his onset depression. As an holistic storytelling device, Iommi does acknowledge the devastation of his accident. However, his upturn occurs with the inspiration of Django Reinhardt (see below) and his pursuit of a new sound. This change in stance may be lommi understanding audiences and musicians being influenced by his style of playing. However, on a personal level, the accident was perceived as a disadvantage. When lommi was asked if his impaired digits directly influenced the future of heavy metal, he agreed they had (McIver 2014, n.pag.). Audiences of heavy metal will appreciate the story of his accident as it directly affects the sound. Conversely, for Iommi, as will be explained below, he had to make numerous changes to both his fingertips and his guitar equipment. McIver (2014) postulates that fretting fingertips for a guitarist should have 'iron-hard callouses on them' (Ibid.). This is true for Iommi as he had to limit using his two impaired fingertips and find alternative solutions (Ibid.). These solutions had to be ingenious: creating new prosthetics for his fingertips and altering the guitar such as filing down the frets, using light-gauge strings and using more gain in the bass socket of his guitar amp (Lima 2015). Perhaps the engineering and, in particular, the welding background of Iommi, contributed to his knowledge and understanding of creating makeshift, DIY, prosthetic solutions.

In terms of disability and adaptive approaches to guitar-playing, the primary point of reference Iommi had was prominent early 20th century jazz guitarist, Django Reinhardt. Even with Reinhardt as a reference point, the influence is based more on Iommi wanting to play the guitar again after his accident, rather than guitar technique. In a practical sense, Reinhardt decided to bypass his paralysed third (ring) and, mostly bypass, his fourth (pinky) fretting fingers on his left hand due to a caravan fire (Givan 2003, p.19-40, and Lubet 2011b, p.46-47). Whereas, Iommi did use his partially-absent digits on his right fretting hand with his prosthetic fingertips. In the Lima (2015) animation, when Iommi was depressed at home in his bed, the manager from his factory job gave Iommi a Django Reinhardt record: 'he [the manager] told me the story; of course, about Django Reinhardt who had lost [correction:

paralysed] his fingers... [in] the fire. And it really... inspired me to really get on with it and start trying to play' (Iommi quoted in Lima 2015, see Iommi 2012, p.21, and McIver 2014, n.pag.). The knowledge of Django Reinhardt adapting his fretting hand using primarily two fingers was the impetus for Iommi to recover from his depressive state and play the guitar again.

Based on this information, it is worth asking: why did Iommi not try to learn to play right-handed to build the callouses on his unimpaired left hand in order to fret the guitar without the use of prosthetics? Iommi (2012) has addressed this:

Probably the easiest thing would have been to flip the guitar upside down and learn to play right-handed instead of left-handed. I wish I had in hindsight, but I thought, well, I've been playing for a few years already, it's going to take me another few years to learn it that way. That seemed like a very long time, so I was determined to keep playing left-handed (p.21-22, see McIver 2014, n.pag.).

As a teenager at the time, lommi probably did not foresee a successful decades-long career playing the guitar. Additionally, as lommi was on the verge of being a touring musician the day after his sudden accident, lommi may have been desperate to play the guitar again with the knowledge he had acquired. Perhaps the compromise for lommi was to adapt the guitar rather than relearn the guitar, which may have taken longer than the solution he chose; although, as he has noted, it would have been beneficial and more efficient in the long term (Ibid.). Because lommi had been playing guitar for a few years, he felt that he had established his technique for his right fretting hand and changing hands would have been counter-productive.

Additionally, Iommi was seeking a new, heavier guitar sound and thus was satisfied with the sonic results when he found an alternative approach. For example, when Iommi was asked about his use of another adaptive technique, the scordatura for the guitar, Iommi says: '[w]e always experimented with Black Sabbath. That was the greatest thing we'd done. We had always tried things that weren't the norm' (McIver 2014, n.pag.). With this in mind, Iommi's reimagined style can be attributed to Black Sabbath's experimentation with sound.

lommi had to find a number of solutions to allow him to place his digits on the strings with the correct pressure and grip. Due to this lack of control, lommi also had to take his time and use his musical sense: 'It was just a matter of practising and persevering with it [adapting musically], using my ears to compensate for my lost tactile sense' (Ibid.). Due to the importance of these solutions, they are chronicled in *Finger Bloody Fingers* (2015) including using a plastic Fairy Liquid bottle melted down to finger-like shapes, changing the heavy strings to lighter strings (initially being banjo strings as light gauge strings were not available at the time), tuning the guitar down, and using more gain on his amp (Lima 2015, see McIver 2014, n.pag.). Although all these solutions contributed to his guitar proficiency, lommi needed the necessary aesthetic control and expression to incorporate these changes. As lommi became a highly-sought-after player in the Birmingham area (McIver 2014, n.pag.), this suggests that this aesthetic control and expression was achieved.

A characteristic established by Iommi in his redefined guitar playing was the popularisation of power chords as this technique only required the use of two fingers (the index and pinky fingers for Iommi; others may use the index and ring fingers). This meant Iommi could bypass using his two impaired digits to play perfect fourth or fifth chords, without the third (Walser 2014, p.2, McIver 2014, n.pag., and Cope 2010, p.31). These chords sonically bring out the 'power' of heavy metal. As Iommi states:

I had to completely re-learn. I was playing with two fingers for a long time and that's how the fifth chords came about. I can't feel a thing... I just have to do it by ear... Put a sewing thimble on your fingers and that would be the equivalent (quoted in Starken 1999 cited in McIver 2014, n.pag. and Cope 2010, p.31).

This shift was a necessity for lommi as he had contemplated switching to the bass guitar to avoid chords altogether and focus on single-note bass lines (McIver 2014, n.pag.). Therefore, it could be argued that Black Sabbath bassist Terence 'Geezer' Butler's more complex bass lines may be a form of 'musical or instrumental prosthesis' to compensate for lommi's technical limitations (see Lubet 2013). Butler's experimental approach to the bass guitar is befitting of Sabbath's approach to music and heavy metal (see McIver 2014, n.pag.). Iommi is better-known for his riff-based guitar work, rather than his guitar soloing.

As Black Sabbath did not have a rhythm guitarist and with Iommi's limitations, Butler would have had more dexterity and been more versatile on the bass fretboard, and thus, facilitated a virtuoso technical display. In addition, the second half of Sabbath's rhythm section, drummer Bill Ward, played in an energetic, frantic style to complement Butler.

'Heavy Metal' as a musical term was established in the late 1960s as an adjective, before becoming a noun in the early 70s, 'and thus a genre' (Walser 2014, p.7). Although other musical genres do have inherent 'power', this 'power' has been a defining characteristic of metal as a genre (see Walser 2014). The 'power' from lommi's new sound is evident across different parts of the Vh1 Classic animation such as when lommi speaks about the inspiration of Django Reinhardt's guitar playing, a fiery blood-soaked tear from lommi's eye drops into flames, akin to a phoenix rising from the ashes (1.55), especially after being told he would not play again (1.40) (Lima 2015). This is reinforced by the credits being surrounded by flames (3.16). Additionally, the animation demonstrates this 'power' when lommi is changing his playing style and his guitar in the pursuit of the new 'heavy' sound. This begins with an oversized lommi looming over his hometown of Birmingham (2.40), then later over a row of houses (2.48), and culminating with lommi playing the guitar on top of the world as a godlike figure for heavy metal (3.00) (Ibid.).

The foundations of heavy metal as a genre are firmly established in the Birmingham area (McIver 2014, n.pag., Walser 2014, p.x, and Cope 2010, p.4-5, p.7). When Iommi was asked about the influence of Aston, he said:

It's a big part of where we [Black Sabbath] came from. It was either being in a gang or being in a band. It was rough. To be in a band... I think a lot of the aggression came out in that, instead of going out and beating the other gang up (quoted in CNN 2004 cited in McIver 2014, n.pag.).

The reference to Iommi's Birmingham roots and factory origins is showcased in the Vh1 Classic animation with Iommi discussing his upbringing depicting a dreary, dark industrial town (0.25), 'thugs' holding baseball bats when Iommi is comparing Birmingham to an

American industrial city, Detroit (0.24-0.27), and donning a welding mask whilst playing the guitar at home (0.34) (Lima 2015).

The members of Black Sabbath felt that rock music in the late 1960s was unrelatable for them (McIver 2014, n.pag., and Cope 2010, p.30). As McIver (2014) explains, Black Sabbath 'played heavy music because they wanted to, and because they needed to—to be noticed and to let out the pressure they felt inside them. And where did this come from? From their surroundings' (n.pag.). Black Sabbath singer, John 'Ozzy' Osbourne, was driven by the: 'fear of working in a factory for the rest of his life' (Ibid.). This is especially relevant as Tony Iommi was left with a permanent impairment (and reminder of where he came from) because of factory work. It has even been argued that Bill Ward's drumming for Black Sabbath was influenced by the rhythms of factory machinery (Poole 2007). In interviews for high-profile television (and music television) networks (BBC and Vh1), Iommi's accident has been discussed against a backdrop of imagery from factories and industrial machinery (Ibid., and Lima 2015). Although Iommi's accident has a direct link to factory work, it is clear that the industrial town of Aston had a profound effect on all members of Black Sabbath and influenced the sound they were seeking to create.

While the story of lommi's LDA and its influence on the birth of heavy metal may be relatively familiar, on a personal level, he did not often showcase or display his LDA. With regards to passing (in terms of physically hiding his impairment, see Brune and Wilson 2013), lommi (2012) states how, after his accident, he would always feel self-conscious about his fingers:

I always felt uncomfortable about it [his LDA] and I always hid my hand. The same with playing: I used to hate anybody seeing it [his LDA and prosthetics]. 'What is that on your fingers?' I later heard that some people actually thought it looked cool (p.28).

People being intrigued by lommi's prosthetic digits was a nuisance for him during his career (which might be why he tried to make them as aesthetically close to fleshy fingertips as possible):

Going through customs with these things [prosthetic fingertips] is another story. I have thimbles in a box and they search your bag and go: 'Ah well, what's this? Drugs?' And then, shock, it's fingers. I've had to explain it to customs on several occasions. And they go: 'Whoah.' Putting my fake fingers away in disgust (Ibid. p.23).

Based on this evidence, it can be reasoned that lommi understands how influential his accident has been to music and the fact, it has influenced, if not created, a sub-genre of music. Iommi embraces the creation of a new sound being related to his own personal childhood environment, however, the accident itself was an annoyance for him in his personal life, his adapted guitar playing, and in certain public settings. Due to the slight nature of his LDA, Iommi is able to pass his impairment in a multitude of ways. These include numerous public-facing and publicity photos such as Figures 2 and 3.

Figure 2 – Iommi using his left hand to hide his impaired fingertips when being photographed at an awards ceremony (Getty Images 2010; for a similar example, see Ibid. 2015).

Figure 3 – Iommi posing for a photo shoot by guitar company, Gibson—curling the impaired digits into his right hand and his index finger into the fretboard (Ibid. 1990; for examples from other photo shoots, see Ibid. 1998 and Ibid. 2009).

The inclusion of these two images (and reference to others) is not to suggest that lommi is deliberately hiding his fingers. For example, the photo shoot poses may have been demanded by the photographer. Instead, the images display how the nature of Iommi's LDA makes the passing of his fingers subtly possible. The loss of Iommi's fingertips was not the first accident to leave a scar. Iommi (2012) explains that when he was a child, he was chased by a bully, fell over, grazed his lip, and thus, scarred his face (p.3). As Iommi (2012) states, 'The scar is still there now. The kids even started calling me Scarface, so I got a terrible complex about that' (Ibid.). Another childhood accident involved Iommi having a sparkler thrown at his face. Based on these events, Iommi passed in a different fashion: 'Over the years the scars disappeared, but the one on my lip still stuck out when I was young, so as soon as I could I grew a moustache' (Ibid.). Therefore, to avoid people staring at the scar on his lip, Iommi had a moustache (throughout most of his musical career), which is a more

permanent (as long as it is maintained) way of passing. Based on Iommi's experiences, the passing of both his lip and his digits could be perceived as a tendency.

In conclusion, when discussing Black Sabbath and their influence on heavy metal, this will inevitably include Tony Iommi's LDA and his accident. In a literal sense, the 'heavy metal' of a large factory machine crushed the ends of two of Iommi's digits directly affecting how Iommi played the guitar. Furthermore, Iommi's factory job would have allowed him to have a greater knowledge of the materials and processes required to create his prosthetic fingertips and the means to modify both the guitar and amplifiers. The UK city of Birmingham, as a home environment for Black Sabbath, provided a space for their musical creativity and a place to escape from. Although it was unfortunate that Iommi's accident occurred as his pre-Sabbath band was about to tour, this enforced respite allowed Iommi to reinvent his guitar style. Had Iommi's factory accident not happened, his guitar playing would have been less distinctive and the difference in Black Sabbath's sound would have been less impactful. Finally, Iommi was self-conscious about his impaired digits. However, Iommi understood how influential his LDA had been on heavy metal as a genre.

3.2 Jerry Garcia, music, impairment, and marketing

This section begins with explaining the nature of the late Jerry Garcia's childhood accident and his perspective on his LDA. This mindset extends beyond his LDA to his music, as Garcia was experimental and open-minded. Garcia and his band, the Grateful Dead, were responsible for the origins of psychedelic rock as a sub-genre, which will be investigated. The minimal media representation of Garcia's LDA during his career may have been influenced by his laissez-faire attitude. However, since Garcia's musical career concluded, his LDA has been branded in numerous public settings, demonstrating the reach that this media representation can have, even if posthumously. As will become apparent in this case study, Garcia's partially-absent finger has become a compelling visual signifier in popular culture.

Jerry Garcia was a famous lead guitarist and vocalist, most known for his work with The Grateful Dead. Garcia lost part of his middle finger on his right strumming hand when on a family camping holiday at the age of four. Jerry, and his brother Clifford (nicknamed 'Tiff'), were chopping wood with Jerry steadying the wood and 'Tiff' chopping. The rhythm the brothers had developed was slightly off causing 'Tiff' to chop off part of Jerry's middle digit (Trager 1997, p.131, Jackson 2000, p.9, and Edmondson 2009, p.5). Garcia's carefree attitude towards his accident suggests that his LDA was a relative non-factor in his personal life. His brother, 'Tiff', recalls how Jerry never blamed him for chopping off part of his middle digit (Jackson 2000, p.9). In fact, Garcia speaks of the moments after his finger was chopped (not yet amputated): 'it was just sort of a buzzing sensation. I don't associate any pain with it' (quoted in Ibid.). For Garcia, any trauma came after the bandages were removed and he realised that the end of his finger was absent (Ibid.). Yet recollecting this experience, Garcia remarks:

...after that it was okay, because as a kid, if you have a few little things that make you different, it's a good score... I got a lot of mileage out of having a missing finger when I was a kid (quoted in Ibid.).

This viewpoint towards his accident could be linked to the fact that a year later his father drowned on a family fishing trip (Trager 1997, p.131, Jackson 2000 p.9-10, and Edmondson 2009, p.5). Garcia speaks of this trauma:

[Father's death] emotionally crippled me for a long time. I couldn't even stand to hear about it until I was about ten or eleven. The effect it had on me was really crushing, maybe because it affected my mother a lot and I sensed that (quoted in Jackson 2000, p.11).

This is understandable for any child who would perceive the woodchopping accident to be far less devastating compared to the death of a parent.

Figure 4 – Jerry Garcia's signature handprint used across his merchandise (Musictoday II 2018, see McDermott 2022).

Due to his physical difference, Garcia was able to use his handprint as a marketing tool (see Figure 4). This fact has been acknowledged by Jackson (2000) with the creation of 'what would in his [Garcia's] later years become an iconic symbol: the unmistakable Jerry Garcia handprint, seen on T-shirts, bumper stickers and car window decals' (p.9). The main and most obvious source of displaying Garcia's LDA is through his merchandise, which became part of popular culture in his late career and posthumously via digital branding of Garcia products and projects (Jerry Garcia Family 2014b). The easily-recognisable image of a handprint, which the majority of people have, is enhanced by the fact that only a small number of people will have a handprint with a partially-absent digit. Garcia recognised this and his estate has marketed this Unique Selling Point (see McDermott 2022). The understated nature of the symbol can act in a similar way to a famous person's signature (as evident in Figure 4 with Garcia's signature) as it is unique to Garcia.

A tribute concert DVD was released to celebrate (what would have been) Garcia's 70th birthday. The front cover displays a handprint on a plectrum with a partially-absent middle digit which has become Garcia's insignia (Kreutzmann 2013).³ The DVD includes Garcia's impairment by highlighting the album cover for *Garcia* (1972) with a disembodied right hand (see Figure 5), and a commissioned hand sculpture of Garcia's right hand (Kreutzmann 2013, and Tom White Studio 2020). Other examples include two websites promoting merchandise with the handprint and Garcia's full body statue in Madame Tussaud's in San

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³ The handprint is that of a left hand, rather than Garcia's right hand. The same is true for Figure 4 and the rest of Garcia's merchandise (Musictoday II 2018, Jerry Garcia Family 2014b, see McDermott 2022).

Francisco, having his right hand in the air with his partially-absent digit on show (Jerry Garcia Family 2014b, Musictoday II 2018, and Merlin Entertainment Group 2017, see McDermott 2022). The highlighting of Garcia's LDA is also suggestive of the 'peace' symbol (the index and middle fingers held up facing forwards), a signifier of the counterculture Garcia was of course part of. This gesture presents disability as non-threatening, which may be the rationale for merchandising his LDA as a source of disability pride. This case study represents how LDA can have little to no effect on instrumental technique, yet can become popular culture art in numerous public settings, even with something as simple as an unusual handprint. This late authentic marker can be related to the Crosby, Stills, Nash, and Young song *Almost Cut My Hair* (1970), with the handprint being a comparably rebellious sign of Garcia's 'freak flag [still] flying' decades later.

The masquerading of Jerry Garcia's partially-absent digit did not happen when Garcia was in the Grateful Dead. If anything, Garcia concealed his partially-absent digit on Grateful Dead album covers such as *Go To Heaven* (1980), and *Built to Last* (1989). In Garcia's side projects, his partially-absent digit on his right hand is slightly visible for the album covers, *Compliments* (1974), *How Sweet It Is* (1997), and *Don't Let Go* (2001), where Garcia holds or plays the guitar with his right strumming hand in full view. The most obvious foregrounding of Garcia's LDA is the self-titled album *Garcia* (1972), which highlights a detached right hand with a partially-absent middle digit, a nod to Garcia's own impairment (see Figure 5). This supports the notion of Garcia using his LDA visually as a celebration of his difference as a matter of fact, rather than in an overt fashion with his merchandise.

Figure 5 – *Garcia* (1972); a rare early reference to his impairment on his first solo album cover (see McDermott 2022).

Garcia's upbringing was unconventional, which influenced the choice of music he played. Garcia's openness is attributed to a teacher in his youth being, 'the guy who turned me into a freak' (quoted in Jackson 2000, p.17). It is interesting that Garcia perceives his LDA as a difference, whereas, his approach to his art is the factor that makes him 'a freak', perhaps making his presentation palatable for audiences to relate to. Jerry Garcia's introduction to the guitar was unorthodox. At the age of fifteen, Garcia acquired an electric guitar and his stepfather taught him unusual open tunings and a few chord patterns (Ibid., p.20-21). When playing the guitar with his brothers, Garcia would play competitively, even joking: 'I play better with four fingers than you guys do with five' (quoted in Ibid., p.24). With practise and dedication, his talents would surpass many non-impaired guitar players.

Garcia's LDA was a permanent reminder for him of his teenage difference with this individualism embraced in his solo career from 1972, as well as his continued authentic freakiness even in older age. Additionally, his successful navigation of the guitar with his LDA confirmed to Garcia that he was a proficient guitarist. This relates to McIver's (2014)

rationale for Iommi's LDA having a significant impact on his guitar playing, due to the fact that it affected his fretting hand (n.pag.). Whereas, for Garcia, his LDA was on his fingerpicking/strumming hand meaning it did not impair Garcia's guitar and banjo playing (especially when he was holding a plectrum). In a similar way to Iommi, Garcia had to be a capable guitarist, and based on experimentation, a flexible guitarist (Edmondson 2009, p.xiii, and Lubet 2011b, p.47). As Phil Lesh, bassist of the Grateful Dead, said the first time he heard Garcia play the guitar: 'I was... amazed at his fluency. He was using a banjo fingerpicking technique on some songs, and, on other songs, he'd play with a flatpick' (quoted in Sievert 2005). Garcia's guitar playing development involved his fingerpicking technique, which was taught to him by an acquaintance in the army (Jackson 2000, p.26). Lesh's ringing endorsement of Garcia's proficiency reinforces the concept that Garcia's LDA had little to no effect on his guitar playing. The Grateful Dead, and in particular, Garcia, were always seeking a new sound. This included being influenced by numerous genres of music such as bluegrass, blues, country, and jazz and various guitar types such as acoustic, electric, steel, and even the banjo (Ibid., p.xi, Edmondson 2009, p.xi, and Malvinni 2013, p.5 and p.13). Garcia's openness to musical genres is evident across his career with: 'rock band the Grateful Dead, his bluegrass band Old and in the Way, the blues-style Jerry Garcia band, or the country-rock group, New Riders of the Purple Sage' (Edmondson 2009, p.xii).

In conclusion, Jerry Garcia's LDA did not negatively affect his guitar playing or his personal life. Instead, Garcia saw his LDA as a difference to be celebrated for making him unique. The reasons for this are due to the nature of his slight LDA being on his picking/strumming hand, and the fact that his accident took place in his childhood, before Garcia even picked up a guitar (both factors which differ to lommi's LDA). Additionally, his father's death would have been more traumatic than the loss of the end of one of his digits. A more significant aspect of Garcia's musical career and personal life is his work with the Grateful Dead and its association with psychedelic rock and all that sub-genre denotes (see Jackson 2000, p.86-102). Similar to lommi, Garcia's surroundings and the thoughts of his bandmates and contemporaries influenced him directly. However, unlike lommi, Garcia would foreground his LDA sparingly as a striking visual signifier—a tool which was employed to mark his uniqueness as a person and as a musician.

3.3 Rick Allen, adapting a career via musical prosthesis

Rick Allen is recognised as *the* one-armed drummer of popular music. This case study starts with an analysis of the manner and timing of his accident. Secondly, Allen's LDA (the loss of his left arm) meant that he had to make significant changes to his drumming technique. Therefore, both the protection of Allen from the public and his diligent practising in private should be investigated, as it allowed Allen to regain the musicianship required to remain Def Leppard's drummer after his accident. Then, Def Leppard's place in the genre of rock, and in particular metal, will be discussed. This is because the band seemed to deviate from their heavy metal roots, placing Allen's LDA and drumming in the background through his simplified technique, and through the high production values of Def Leppard records at the height of the band's fame. Finally, although Allen's LDA media representation is backgrounded in Def Leppard, on a personal level it has been foregrounded. This has similarities with Jerry Garcia because both foregrounded their LDA after their musical peaks.

Rick Allen lost his left arm in a car accident on New Year's Eve 1984 during the recording of Def Leppard's later-titled album, *Hysteria* (1987). This album title was a reference to the media coverage surrounding Allen at this time and Def Leppard's lengthy hiatus (Jones 2014, and Klosterman 2001, p.24). The name has also been used for a feature film which dramatises Allen's accident called *Hysteria – The Def Leppard Story* (Mandel 2001). The prevailing thoughts after Allen's accident turned to the uncertainty surrounding Allen's future in Def Leppard. At the time, it was deemed inconceivable for a one-armed drummer to play in a high-profile rock band (Klosterman 2001, p.24). This event in both Allen's life and Def Leppard's career was seminal as it created a high level of precariousness and raised a number of music-related questions such as: would Allen be able to play the drums again and at the level that is expected of Def Leppard, their representatives, and their audiences? How would Allen play the drums if he did return and would the rest of the band have to change to compensate?

BBC Television's *Fighting Back* (1992) is the main source which explores Allen's return to drumming in great detail (although the Vh1 Def Leppard episode of *Behind the Music* does mention Allen's return to a lesser degree) (Thomas 1992, and McNamara 1998 and 2010).

Fighting Back was an episodic TV series hosted by the actress Lynn Redgrave running for one series of ten episodes in 1992. Each thirty-minute episode was centred around a public figure who had been through a personal trauma, and discussed how they navigated their lives to eventually 'fight back' (see Silva and Howe 2012, p.175 and Buck 2023, n.pag). The episode on Allen includes: Allen's time in hospital; his isolation from the rest of Def Leppard for technical reasons; and the low-key warm-up Irish tour with a second drummer, returning to full independence at the large-scale, open-air Monsters of Rock Festival at the prestigious Donington in 1986, which is narratively presented as the culmination of Allen's return. Therefore, as this presentation covered the breadth of Allen's journey to his on-stage return with Def Leppard, it should be examined here. It is worth noting that this episode aired in 1992: it was produced over 7 years after Allen's accident, meaning that most of any 'hysteria' from Allen's return would have subsided.

Allen explains whilst recuperating in hospital after his accident that, although he was depressed and did not want to listen to music, his brother brought in a stereo (akin to lommi's factory manager giving lommi a Django Reinhardt record). Allen used his feet (his right arm was also badly injured in the car accident) on the foam rubber at the edge of his hospital bed (which helped him to sit up) to attempt to play along with his favourite songs. This process gave Allen the inspiration to use his left foot as a direct replacement for his absent left arm. From this, discussions between Allen and the electronic drum company, Simmons, were had to set his drum kit up with more foot trigger pedals (Thomas 1992, Jeffrey 2011, Jones 2014, and 65 Drums 2017). As Def Leppard were already a successful rock band, Allen would have been able to obtain state-of-the-art equipment. This should not detract from the fact that Allen had no point of reference for his reimagined technique and instrumentation, as there were no well-known one-armed drummers to learn from (and no Internet capabilities to discover lesser-known ones).

Once Allen sat behind the drums again, he isolated himself from the rest of Def Leppard to get his musicianship to a level he could accept (Signed Media 2005, and Jones 2014).

Although Allen was able to perform in the recording studio whilst rehabilitating, he did not have the confidence to perform in public or even privately in front of the rest of the band.

Along with Phil Collen (guitarist) and Rick Savage (bassist), Def Leppard singer Joe Elliott emphasises Allen's isolation during the recording of *Hysteria* (1987):

[Allen] ask[ed] specifically to be locked away in a room where nobody could hear him make the mistakes, he was obviously going to make re-learning to play. We were very lucky that we had basic drum tracks on tape so we could carry on making the album. So, there was (sic) the four of us locked in one room and he was somewhere else and we just let him get on with it (Elliott quoted in Thomas 1992).

Allen's meticulous dedication has parallels with accounts of heavy metal guitarists, Yngwie Malmsteen and Steve Vai, sacrificing their school, social, and personal lives in the continued pursuit of virtuosity on their instrument (Walser 2014, p.99-100). Although Allen was not seeking virtuosity per se, re-learning the drums with one arm would require a similar assiduous mindset.

To begin Allen and Def Leppard's long-awaited return to touring, their management arranged for them to perform a few dates in Ireland accompanied by drummer Jeff Rich from rock band Status Quo, to support Allen as a secondary, assistive drummer (Jones 2014, McNamara 1998 and 2010, and Thomas 1992). As Allen recalls:

We [Def Leppard] wanted to do a small warm-up tour before the last tour, which was the Hysteria tour, and we ended up in a place on the South West Coast of Ireland called Ballybunion [laughs] and I think the roller disco was on after us [laughs] (quoted in Thomas 1992).

The desired, low-key nature of these initial concerts (hence the joke regarding the roller disco) suggests that, despite extensive practise, Allen did not want to perform alone in front of a public audience, as he was not comfortable until he had trialled his new reconceptualised drumming technique. Jeff Rich's role as a secondary drummer would involve intervening if Allen made a mistake, which helped with Allen's confidence (Saccone 1988, p.16-22). At the end of these tour dates, Rich dismissed himself as he felt Allen could play the drums independently (which Allen did for half a concert when Rich arrived late)

(Thomas 1992). This affirmation from one of Allen's contemporaries would have been the self-actualisation of numerous hours working in isolation and a reward for his dedication to his craft.

The utilisation of a second drummer by Allen is analogous to jazz pianist Oscar Peterson using an additional pianist to compensate for his diminished but redefined piano playing after his stroke (see Lubet 2013). As Lubet (2013) has argued 'any instrumental prosthesis will, like any limb or organ prosthesis, require a degree of creative re-imagination' (Ibid., p.159). Furthermore, Lubet (2013) claims 'timbrally, the most effective piano prosthesis for any pianist is, of course, an additional pianist' (Ibid., p.163). For Allen, 'the most effective' instrumental prosthesis early on was a second drummer. The scrupulous negotiation of various factors facilitated Def Leppard's successful return to touring. These factors included careful preparation by Allen, the support of his bandmates, and the reassuring role of a second drummer during a warm-up tour.

Rick Allen's first time behind the drum kit with full independence (sans Jeff Rich) was at the iconic Donington in 1986. This seminal gig was an important turning point for Allen and the band as a whole (Longfellow 2002 and Halfin 2011, p.25). Although singer Joe Elliott was reluctant to bring attention to Rick Allen, as the concert progressed, he felt compelled to do so, based on the crowd's reaction (Longfellow 2002). When Elliott did introduce Allen, the fans erupted in cheers with 70-80,000 people screaming. This was an emotional moment for all involved, especially Rick Allen, and made the band stronger as a unit (Ibid., Jones 2014, Saccone 1988, p.16-22, McNamara 1998 and 2010, and Thomas 1992). Throughout the tour, Rick Allen received an ovation every time he was introduced in a new city (Jones 2014).

With Def Leppard's return to Donington two decades later, Elliott provided a more sensationalised speech:

Rick Allen [stands up, taking an ovation from the audience]. See the hairs on my arm; they're up now. Just like they were in 1986. It was one year before we [Def Leppard] released the *Hysteria* album and there we were. We weren't really sure what was going to go on. But he [Allen] fought his way back from a terrific injury... this was the

spiritual rebirth of this boy at the back. And it'll always be Donington to us. Make some noise for Rick Allen, will you? [A long ovation]. [Elliott to Allen] Stand up again, man. This is never gonna (sic) happen again. [Another ovation]. It's the human spirit winning over anything. This is the man (quoted in McHugh 2011).

The audience at the first Donington concert would have been pondering if Allen would be able to drum again and play the existing (and new) Def Leppard material to an acceptable level, compared to before his accident. Although these two concerts (Donington 1986 and 2009) were always going to be steeped in sentimentality towards Allen, as he has remained Def Leppard's drummer throughout their career, this suggests that his drumming ability had been restored in the eyes of the public and has therefore 'overcome' (see Silva and Howe 2012, p.175, and Buck 2023, n.pag.).

At this point, it is important to contextualise Def Leppard's position in the genre of heavy metal to understand several tropes which could have shaped the perception of Rick Allen's drumming. This position shifted across Def Leppard's career and is therefore an aspect of Allen's drumming which needs to be considered. Def Leppard started as a band in the late 1970s, rehearsing in a dilapidated factory in the industrial, steel-making city of Sheffield (McNamara 1998 and 2010). These origins are reminiscent of Black Sabbath in Birmingham. Singer Joe Elliott states that, when he was young, Black Sabbath were one of the: 'only three bands that mattered' (quoted in Szatmary 1987, p.205).4 Def Leppard were part of the second wave of heavy metal in the UK in the late 1970s, coined the 'New Wave of British Heavy Metal', or 'NWOBHM' for short (Walser 2014, p.11-12, and McIver 2014, n.pag.). However, 'members of ... Def Leppard claim to hate the term [heavy metal]' (Walser 2014, p.6, see Szatmary 1987, p.205). After their early albums, Def Leppard made a conscious effort to separate themselves from what they were seeing as the stigma of heavy metal, which followed Black Sabbath throughout their career. In terms of heavy metal tropes, other than forming in an industrial city, Def Leppard did not wear black or gothic clothing, and did not use an occult aesthetic or lyrics in their music.

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⁴ The other two bands were Led Zeppelin and Deep Purple (see Ibid.).

Due to this considered distancing, Def Leppard were deemed to be 'too commercial' to be a 'true' metal band (Earl 2009, p.33). Earl (2009) explains how musically Def Leppard moved from 'the melodic rock field further towards the field of large-scale production' (Ibid., p.43), versus overt technical displays of virtuosity.⁵ This is evident when eminent producer Robert 'Mutt' Lunge became the entrusted producer for the band, and co-writer of a large number of songs on Pyromania (1983) and, on the album after Allen's accident, Hysteria (1987). The recruitment of Lunge made the band a more cohesive unit, with a key feature of the recordings being the multi-tracked layering of vocals and other instruments (Earl 2009, p.43-44, and Longfellow 2002). In fact, Allen's accident necessitated a more direct and even simple drumming style which, Elliott recalls, was what the band was striving for (Longfellow 2002). After Allen's accident (or at least after Lunge's hiring), Def Leppard had transitioned from their humble Sheffield beginnings to the commercial side of metal. Their new direction led to pop chart success featuring a number of pop ballads, which deviates far from the heavy metal influences on the early albums (Earl 2009, p.44). The presence of pop ballads in a previously male-dominated genre may have been an affront to 'die hard' metal fans (Klosterman 2001, p.24-25). In the 1980s, metal as a genre had a widening appeal moving from the male-oriented early heavy metal to both an older and female audience base (Walser 2014, p.12-13). In Klosterman's (2001) account of Def Leppard, he stated that they were an MTV-centric band, with Joe Elliott being the focal point and the other members of Def Leppard being backgrounded and even 'interchangeable', which was fairly common for metal non-vocalists in the MTV era (p.29-30). This is of particular interest because Allen has a clear visual signifier—an absent left arm, which would distinguish him from all other members. Therefore, the fact that Allen wore shirts (with an empty sleeve) in music videos after his accident may have helped keep the focus on Elliott.

When researching numerous music videos of Def Leppard, it is apparent that Allen's visual representation has differed before and after his accident. Before his accident, Allen would mostly play the drums shirtless (thus displaying his torso, shoulders, and both arms in full). Examples include: *Foolin'* (Mallet 1983a), *Photograph* (Ibid., 1983b), *Too Late for Love*

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⁵ Although guitarist Steve Clark (1960-1991) was 'classically trained', and fellow guitarist Phil Collen 'studied mostly jazz' (Walser 2014, p.92).

(Mansfield 1983), and *Rock! Rock! (Till You Drop)* (Nakae 1983). After his accident, the drummer was almost always wearing a shirt or a jacket with an empty sleeve. Examples include: *Animal* (Freel and Pellerin 1987a), *Women* (Ibid., 1987b), *Armageddon It* (Isham 1988a), and *Pour Some Sugar On Me* (Ibid., 1988b). Of course, this correlation may not be solely related to Allen's LDA. Other factors such as being conscious of putting on weight, or ageing, or instructions from Def Leppard's management, for example, may have contributed to Allen covering up his torso. Furthermore, the new direction of Def Leppard becoming a commercial MTV metal band, with the emphasis on foregrounding Joe Elliott as the frontman, may have been a consideration (see Klosterman 2001, p.29-30). Yet it is striking.

On a personal level, Rick Allen has foregrounded his LDA to market the absence of his left arm, in a similar fashion to Jerry Garcia's partially-absent digit. This merchandising takes the form of Allen's 'StikRick' drawing, which is a one-armed stick-figure holding a drum stick in his right hand and having Allen's curly hair (Figure 6, see McDermott 2022). There are examples of visual media utilising the StikRick drawing such as: in Halfin's (2011) illustrated Def Leppard book with Allen's signature (p.24), and on a plectrum (p.25); on Allen's headphones during a Def Leppard concert (McHugh 2011); and on Allen's personal website as the official logo for the 'Life's Great: Be A Rockstar' merchandise (Allen 2020b). Arguably, such promotional use of StikRick presents Allen's LDA in an inoffensive manner, similar to Jerry Garcia's handprint. In fact, StikRick presents impairment with the simplistic, arcane stick-figure, akin to that of a child's drawing of Rick Allen. Def Leppard as a band removed themselves from the heavy metal associations before Allen's accident. Personally, Allen has removed his LDA representation (mostly) away from Def Leppard and the potential associations of the 'sex, drugs, and rock 'n' roll' lifestyle of commercial rock/metal music (McNamara 1998 and 2010). The innocent stick-figure is used due to the fact that Allen was able to utilise merchandise to fund his advocacy projects (Allen 2020a and 2020b, Cooper 2009, CROP Creative Media 2013, Ellis 2016, and McDermott 2022). This foregrounding of Allen's LDA is controlled away from Def Leppard, and can be used subtly as an endorsement of his charity work, with certain nods to his rock persona.

Figure 6 – Allen's 'StikRick' drawing, with an absent left arm and therefore, 'celebrating' his LDA representation (Allen 2020b, see Campus Sports (2015) for Allen's advice to 'celebrate your uniqueness').

In conclusion, Allen's absent left arm was inevitably going to gain significant media attention because it was lost in such a dramatic fashion and, unlike Iommi and Garcia, it affected Allen at the height of his professional music career. To avoid some of the 'hysteria' surrounding his accident, Allen protected himself and was protected by others in order to regain his drumming technique in a unique, reimagined manner. This includes in the recording studio with the other members of Def Leppard and on tour with second drummer, Status Quo's Jeff Rich. The new direction Def Leppard were moving in both musically and in production, (which would have happened regardless of Allen's LDA) may have aided in Allen changing his drumming to the level required to play the back catalogue of Def Leppard and future songs on tour. Although Def Leppard wanted Allen to play a more simplified drumming technique (see Longfellow 2002), these changes do not detract from his drumming ability, as Allen's utilisation of his left leg and rearrangement of a hybrid drum kit (part acoustic, part electronic) took tremendous dedication (see 65 Drums 2017). Additionally, this divergence would have (if not already) shifted the focus of performance onto frontman Joe Elliott, allowing for the backgrounding of Allen's LDA in Def Leppard. This would have been emphasised by Allen choosing to wear shirts and jackets in music videos after his accident. Unlike before, where Allen would be shirtless; flaunting his body and the traditional masculine physicality of the act of drumming, particularly in rock music. As evidenced by Allen's use of StikRick, Allen is able to foreground his LDA representation for advocacy

purposes by using an inoffensive, child-friendly stick-figure (see Figure 6 and McDermott 2022). This deviates from his rock music, demonstrating that LDA representation is context-dependent.

The three case studies researched thus far may suggest that the most prominent musicians with LDA in recent popular music history are limited and relatively homogenous in type. Tony Iommi, Jerry Garcia, and Rick Allen are all male rock instrumentalists who had their musical peaks decades ago (arguably the 1970s and 80s). Therefore, it is important to shift from this where possible, for it does not tell the wider story. My final case study should achieve this, as it is a contemporary contrast. She is a female pop singer who has used the bionic aesthetic for a number of artistic prosthetic designs to supplant her partially-amputated leg. She infiltrated the mainstream in 2014 with the music video for her single 'Prototype' (Farahmand 2014 and Modesta 2014). This musician is Viktoria Modesta.

3.4 Viktoria Modesta, gender, pop, and prosthesis

This case study of Viktoria Modesta will begin by discussing Modesta's LDA which, unlike the other three case studies, was by choice rather than by accident, which provided opportunities for her as a 'bionic pop artist'. Then, as Modesta operates in pop music, the conventions of the genre will be examined to understand where Modesta fits within this context. Thirdly, the use of prosthetics in pop music and popular culture by Modesta will be explored in relation to issues surrounding disability. Finally, the branding of Modesta is directly related to her LDA, which will be discussed because it can be compared to Rick Allen and Jerry Garcia. To underpin this section, Modesta's most notable work, the music video for *Prototype* (Farahmand 2014) will be scrutinised in line with certain key themes covered.

Modesta's traumatic birth meant that the bone structure in her left leg was affected, thus causing problems throughout her childhood. Modesta's childhood in late Soviet-era Latvia led to restricted access to high-quality prosthetics and medical aid, hence her having 15 unsuccessful surgeries (Stańczyk 2016, p.75, Channel 4 2014, and Virtual Futures 2016). After moving to London, at age 15, Modesta decided she wanted to have the lower part of

her leg amputated. However, it was not until she was 20 years old that a doctor would support a medical intervention by performing her amputation (Stańczyk 2016, p.75). In the *Prototype: The Making Of* video (a behind-the-scenes mini-documentary of the music video), Modesta speaks of her decision:

There needs to be a sense of me taking control over my body. And at that point, I decided that I needed to have my leg removed. When I woke up from my operation, opening up the covers and not seeing anything there at all—it was like Christmas (quoted in Channel 4 2014).

The medical and social issues surrounding Modesta's damaged leg highlight how having her leg amputated was seen as a potentially and even actually liberating experience for her. The three musicians studied previously in this chapter had healthy limbs and digits before their accidents, which were removed in an instant. Whereas, Modesta had time to consider her decision and needed to find a doctor who agreed to her amputation.

Perhaps unusually for a visibly physically-disabled woman, Modesta became a pop artist and, with her use of interchangeable prosthetics for her below-the-knee left-leg amputation, she has been coined a 'bionic pop artist' (Autodesk 2017, and Dutch Digital Agencies 2019). Therefore, it is necessary to investigate the conventions of pop as a genre to understand Modesta's place within it, particularly her most significant work for the music video, *Prototype* (Farahmand 2014). This music video entered the mainstream by its placement during an advertisement break for the 2014 series finale of singing talent show, *The X Factor*, on the UK television network, ITV. This video was broadcast to millions of viewers (Bryant and Mawer 2016, p.87). In addition, the video was released by Channel 4, two years after the London Paralympics in 2012, to further the disability awareness movement (Channel 4 2014). It is worth noting that Modesta was part of the 2012 Paralympics Closing Ceremony, assuming the role of 'The Snow Queen', which was an early introduction to Modesta's cyborg representation to a large-scale audience (CDI 2017). As Modesta states:

Everything ... changed after I did the Paralympics. I was ... all of a sudden part of this global movement that was happening everywhere and that everybody was talking about. It opened discussion[s] [regarding]: what is disability? How people are perceived (quoted in Channel 4 2014).

Pop as a term is often maligned as 'signifying disposability and inferiority' (Rojek 2011, p.1). Disabled people are often wrongly perceived as being 'inferior' and the 'disposability' can be applied to the interchangeable prosthetics used by Modesta in her work. Pop as a genre is accused of being pushed for commercial needs, whereas, other popular genres are depicted as being 'more authentic' because they 'truly reflect the people's concerns, practices, traditions and aspirations' (Ibid.). Despite this, pop has mass appeal and is appreciated even though it has 'associations with commercialism, manipulation and low taste' (Ibid., p.1-2). For Modesta, her music and media representation are centred entirely around her LDA and in particular, the prosthetics she uses, which would seem to run counter to pop's inauthenticity. The use of *Prototype* and the high-profile collaboration places Modesta in the realms of commercialism. Nevertheless, the 'manipulation' of pop audiences has the potential to change perceptions surrounding disability.

Frith (2001) categorises pop music into four groups (cited in Rojek 2011, p.2-3). The first categorisation is 'general appeal', describing the *Got Talent* business model as: 'songs and middlebrow performers who, in the majority of cases, aim for the lowest common denominator of emotions' (Rojek 2011, p.2-3). Modesta's *Prototype* was placed within *The X Factor* final, which helped to subvert this notion by trying to present disability as not an inferior state but something to be celebrated, perhaps even revered. This relates to the second categorisation of pop music as 'light entertainment', which typically does not question audiences with the music and performers being controlled by pop music industry figures (Ibid., p.3). *Prototype* seeks to challenge the former (questioning audiences) directly. However, Modesta did not dictate the latter; instead yielding some control to Channel 4 (who helped create the video for the single 'Prototype') and *The X Factor* brand.

The third categorisation involves 'commercial imperatives' which means that pop music is: 'a business rather than an art form' (Ibid.). The association of *Prototype* with *The X Factor*

could be accused of using disability for profitability and shock value rather than any form of social commentary (see Houston 2019, p.709-710). The final categorisation is 'personal identification'; a music to, 'appeal to the masses... Pop works with clichés, stereotypes and melodrama to connect with individual listeners' (Rojek 2011, p.3). Although putting *Prototype* in the advertising slot during *The X Factor* final may not have had mass appeal, it would have been watched by millions of people. Again, disability is presented using several pop music tropes including sexualisation, which can be negative because this presentation may suggest that to be accepted as a disabled person, one must be beautiful. Pop music can attempt to provide resistance through political and/or aesthetic terms (Ibid., p.2-3), which *Prototype* is trying to achieve. On a personal level, this was realised. Holistically, arguably though, this was not.

Although *Prototype* made an impact on a large audience and gained significant media attention, Viktoria Modesta did not follow up on this initial success (Stańcyzk 2016, p.76). This may be due to the fact that it is not part of her remit as a 'bionic pop artist' (Autodesk 2017, and Dutch Digital Agencies 2019). In this instance, 'pop' may not refer specifically to 'pop music'. Instead, 'pop' refers to 'popular culture'. In various speeches and interviews, Modesta has crossed over many fields ranging from music, acting, and art, to science and technology, through to prosthetics and fashion (Dutch Digital Agencies 2019, Hayman 2016, Modesta 2017, and IMDb 2020). Notable collaborations include: being 'The Snow Queen' at the Paralympics; becoming an ambassador for the MIT Media Lab; and Sonifica, which involved using tusks as a futuristic keyboard which Modesta could play (AutoDesk 2017, CDI 2017, Dutch Digital Agencies 2019, Hayman 2016, Virtual Futures 2016, and The Archiologist 2016). Crossover has also been evident in a number of her publicity photos wearing prosthetics in *The Times* newspaper and *Grazia* magazine (TEDx Talks 2013). As previously suggested, with Modesta wanting to be a 'popular culture artist', LDA representation has the potential to expand beyond music-related depiction to embrace portrayals of stardom and celebrity in a variety of mainstream media.

The context for prosthetics and how Modesta has posited them in pop music by drawing on popular culture should be explored. Stańcyzk (2016) explains that prosthetics allow disabled people to move away from the 'victim status' of disability to that of an empowered

individual (p.68). This use of prosthetics can be perceived as a form of, 'body modification, such as dieting, piercing, tanning and bodybuilding. Viktoria Modesta... [is an] extreme bodybuilder' (Ibid., p.69, see CDI 2017). With the interchangeable nature of prosthetics, 'body modification' can vary instantaneously, as is the case in the *Prototype* video (Farahmand 2014). The mantra of the *Prototype* video is: 'Forget what you know about disability' (Ibid., and Stańczyk 2016, p.68). Modesta displays a new human prototype incorporating both her natural partially-absent leg in the bed scene (2.43-2.48) (see Farahmand 2014) and her artificial prosthetics, which changes almost scene-to-scene: 'she has functioned as a glitch in the system to achieve celebrity status; she is known as a "glamputee", reclaiming the traditional image of women while ostensibly reinterpreting it' (Stańczyk 2016, p.69). Furthermore, Stańczyk (2016) states: '[i]n the case of Modesta ... technology is a tool of subversion, combating prejudices about disabled people, and even creating an alternative hierarchy. Rejecting medical discourses and disciplinary practices can be a medium of renewal' (Ibid., p.72). Based on Modesta's perspective towards her upbringing and her amputated leg, this is accurate.

Modesta believes that if she incorporates bionic prosthetics in her professional career, they need to relate to her personally. When she was growing up in late Soviet-era Latvia and during her many occasions in hospital, she created her own fantasy world away from her reality influenced by Disney and other Hollywood films (Dutch Digital Agencies 2019). These films included Edward Scissorhands (1990) and The Little Mermaid (1989), both involving hands and legs respectively, which were 'non-human appendages' (Dutch Digital Agencies 2019 and McDermott 2022). Modesta comments on this influence: 'the lack of structure that I had while growing up isolated away from society and locked away in my imagination gave me the freedom to see all culture as a canvas' (Dutch Digital Agencies 2019). This isolation is comparable to Rick Allen relearning the drums in the recording studio. When Modesta moved to London as a teenager, she was heavily influenced by the subculture of fetish clubs. Modesta describes these clubs as a 'grown-up version of Disney' (Ibid.), and the 'perfect platform for some experimentation' (Virtual Futures 2016). This is analogous to Tony Iommi searching for his new 'sound' and solutions to enable him to play the guitar after his accident. Later, Modesta was influenced by conceptual artists such as Matthew Barney and Alexander McQueen (Dutch Digital Agencies 2019). The director of Prototype,

Saam Farahmand, incorporated these elements for the music video; capturing Modesta's personal history minus any vulnerability from her childhood (Farahmand 2014, and Channel 4 2014).

Although a 'sci-fi' LDA representation may appear to be a radical visualisation of disability, Modesta's integration of having movie character-esque alternative limbs and being influenced by fetish nightclubs (extending to fetishised cyborg limbs teamed with conceptual art) facilitates a new cyborg aesthetic (see Braidotti 2013, p.3, and Haraway 1991, p.163-164). Modesta's main focus is on making eye-catching prosthetic designs for her media appearances. This has been explained by her prosthetic maker, the founder of the Alternative Limb Project, Sophie de Oliveira Barata (see The Alternative Limb Project 2015a and 2015b): '[Prosthetics are an] ... unspoken form of communication—their [the wearer's] thoughts are being translated through their limbs... [Prosthetics are] like tattoos but... extreme, full on' (Channel 4 2014). For Modesta, LDA is reduced to purely aesthetic concerns. Whereas, for an instrumentalist, the use of prosthetics would likely lean towards function.

The significance of the prosthetic legs used in the *Prototype* music video should be addressed, as the impact of the aesthetic nature of the prosthetics is central to the video. Modesta's 'spike leg' has been described as 'an incarnation of monstrous femininity and a superhero—a pop cultural cyborg overcoming biological deficiencies' (Stańczyk 2016, p.68). This 'monstrous femininity' has been captured by Modesta's 'spike dance' at the beginning (0.13-0.17) and the end (4.56-6.01) of the video, with the enhanced reverberant sound of the 'spike' on a glass floor and her rapid, exaggerated motions (Farahmand 2014). The 'superhero' can be perceived with the Betty-Boop inspired cartoon character (an animated version of Modesta) with the 'spike leg' puncturing monsters, influencing a young girl watching the cartoon on television to replicate these movements with her dolls (1.18-1.37); and the tattooing of this character on a person's back (2.27 and 4.26-4.28, see Figure 8) (Ibid.). Modesta describes the 'spike leg' as, 'an important cultural piece' (The Archiologist 2016), and, 'the application of design and augmentation of the body's silhouette' (CDI 2017). Farahmand also comments on the leg: 'collectively everyone felt that a spike... was

such a powerful and immediate fantasy prosthetic that we was (sic) surprised we hadn't seen [such a prosthetic before]' (Channel 4 2014).

The influence of the 'spike leg' prosthetic and other iconic images from the *Prototype* music video have been displayed in numerous interviews and public appearances (CDI 2017, Dutch Digital Agencies 2019, Hayman 2016, Modesta 2017, The Archiologist 2016, and Virtual Futures 2016). The tapering of the leg to a point changes Modesta's mobility when manoeuvring on stage and does not attempt to be anatomically correct, which makes it the most impactful prosthetic Modesta uses. This is not to say that the other prosthetics Modesta wears in *Prototype* are not visually striking versions of anatomic legs. These include a light-up prosthetic leg (1.48) and a crystallised prosthetic leg (3.14) (Farahmand 2014). The purpose of the numerous prosthetics used in *Prototype* is not for function (except for mobility). Instead, Modesta's prosthetics are presented as, 'fashion items and art projects', which is evident with her collaborations elsewhere (Stańczyk 2016, p.76 and p.79).

Unlike songs featured in the other case studies, the lyrics of Modesta's single, 'Prototype' (Modesta 2014), help reinforce the message of creating a new cyborg aesthetic to change perceptions about disabled people for the future. The lyrics suggest that Modesta's bionic appearance as a 'new kind of pop artist' is indeed a 'prototype' for futuristic disability representation. This is not in a literal, everyday sense; more a 'sci-fi' LDA representation which incorporates technology to its fullest in a utopian fantasy (see Braidotti 2013, p.3, and Haraway 1991, p.163-164). The future-oriented identity formation and experimentation is apparent with lyrics such as:

Another life filled with parts, circuit boards, connecting hearts, Nostalgia for the future ...

Assemble me piece by piece. Strip away the incompletes.

The model of the future.

Colliding minds, it's just a start.

Feel the sparks. We're building art.

It's the vertigo of freedom. (Modesta 2014).

Of course, the simple and repeated line, which makes up the chorus, amalgamates all of these aspects:

I'm the pro. I'm t

The presentation of disability through cyborg idioms has been embraced by popular culture and can at its best be perceived as a new form of disability pride. Ostensibly, the lyrics suggest new body styles through the incorporation of cybernetic machinery. This explicit ideal is shown as an inevitable 'future' for humanity. However, the lyrics (and as evidenced later, the video) present this ideal in an egocentric, messianic manner. Modesta is presenting her personal story and is not addressing wider issues. As Stańczyk (2016) highlights, the lyrics frequently refer to Modesta with the possessive 'I', rather than the purpose of the Paralympic movement, which should be 'we' as a collective (p.77). Additionally, in the music video *Prototype*, only one other amputee is shown (Farahmand 2014). Conversely, it could be argued that there are several able-bodied people within the music video who have been influenced by Modesta's representation suggesting a shift in public attitudes (Ibid.). When referring to the Paralympic movement and Channel 4 projects 'Meet the Superhumans' (Channel 4 2012) and 'We're The Superhumans' (Channel 4 2016), the latter specifically teams disabled musicians with disabled sportspeople. This representation makes the message of the project more impactful as it presents a disabled community, rather than a solo, personal story.

Stańczyk (2016) argues that:

The main plot line of this video clip concentrates on VM's cult in some historically undefined police state... Her prosthesis wields superpower, but its connotations with new identity and individuality are more important, encouraging people to stand up for themselves (p.76).

This 'individuality' is clearly influenced by attitudes towards Modesta's disability and background in Latvia. This disability 'movement' is further enhanced by denouncing the notion of disability as asexual with 'sexual relations with a man and a woman while not wearing any of her prostheses, suggesting that her identity is fluid, more complex, nondualistic and receptive' (Ibid., p.77). Modesta and Farahmand consciously combine the physical amputation with a sexualised pop culture. However, as Stańczyk (2016) postulates: 'why combine the two instead of creating a new language based on the plot of female subversive powers? An uncontrollable and therefore threatening force is reduced to a sexualised object' (Ibid.). Additionally, Prototype begins by addressing social issues of disability, however, over time visually, the music video reflects Modesta's own personal story involving her background, her LDA, and her status as a model (Ibid.). Based on this information, Prototype had the potential for social change, yet this was not realised because many tropes associated with the genre of pop such as appealing to the lowest common denominator by using sexualisation for titillation were dominant (see Rojek 2011, p.2-3). Within the genre of pop, prosthetics have an interesting place. However, when prosthetics are presented in stereotypically gendered ways, they become simply another part of popular music. If the 'creation of new corporeal narratives' shifts into different areas of 'post-human and post-gendered concepts', this representation has the potential to be transcendent (Stańczyk 2016., p.73).

Figure 7 – A picture of a person shown holding a knife after cutting off their own left foot (with a 'peace symbol' displayed in their left hand, as a sign of unity with Modesta's cause) (Farahmand 2014).

An important moment in the music video is when Modesta is shown an image of a smiling person sitting on the floor with a bloody amputated leg (the only other amputee in the video). The person is displaying the 'peace symbol' in one hand and holding a knife in the other, as the line 'They believe in you Viktoria' (4.05) displays on screen (Figure 7). As with the examples of Jerry Garcia's handprint (Figure 4) and Rick Allen's StikRick (Figure 6), this may be thought of another, if extreme, display of disability solidarity (see McDermott 2022). Figures 4 and 6 display disability as non-threatening; whereas, Modesta has directly influenced a follower of hers to horrifically chop off their own leg (hence the knife in hand) to have LDA similar to their idol, being somewhat reminiscent of the horror animation of lommi's LDA (Figure 1). However, in *Fingers Bloody Fingers* (2015), the comic-book, stylised nature of the video and the exaggerated level of blood spouting from the fingers makes the presentation of lommi's LDA more palatable for audiences (Lima 2015). In Figure 7, LDA is presented in a deliberately shocking fashion (with blood on the floor and residual limb in view); an obvious reference to Modesta choosing to have part of her leg amputated as a young woman. Although presented in an overstated fashion, the person in the music video

was willing to become an amputee; as part of Modesta's 'vertigo of freedom' (Modesta 2014, and Farahmand 2014). This sense of disability as a movement has been emphasised by the taglines in *Prototype* such as: 'Forget what you know about disability' (0.02); 'A new kind of pop artist' (0.17); and 'Some of us were born to be different... Some of us were born to take risks' (6.00) (Farahmand 2014). The most realistic 'risk' taken in the video is displayed by the scene surrounding Figure 7.

Figure 8 – The tattooist applying the Betty Boop-style tattoo of Modesta, with Modesta's brand symbol itself already tattooed on their own hand (Ibid.).

Across the music video, Modesta's LDA brand is presented in two different forms: a symbol which is an abbreviation of Modesta's name 'VM' (akin to the spike leg shape), and the Betty Boop cartoon character with the left-leg 'spike' to depict Modesta. The 'VM' symbol is shown: when a schoolboy scrawls it into a school desk (4.21); being held up to Modesta on a piece of paper by an interrogating general (3.57 and 4.02); and on a tattooist's hand (4.26-4.28, see Figure 8). The cartoon character is displayed: when a young girl is watching the cartoon depicting Modesta puncturing monsters with her spike leg (1.18-1.37); in the bed scene with a picture in the background (2.43-2.48); and being tattooed on a person's back (2.27 and 4.26-4.28, see Figure 8). This culminates with the completed tattoo of the cartoon

Modesta on the person's back, as is evident in Figure 8, where the 'VM' symbol on the tattooist's hand comes into shot when the camera pans across (4.26-4.28) (Ibid.). Modesta has used these two symbols after the *Prototype* video, for her own branding. The 'VM' symbol is part of Modesta's identity as shown in different interviews (CDI 2017, and The Archiologist 2016). This logo is also part of Modesta's merchandise (Modesta 2020). Additionally, Modesta has shirts which display her most notable prosthetic, the 'spike leg' (Ibid.). This particular merchandising is a subtle form of disability pride (akin to Jerry Garcia and Rick Allen, also known as 'cripmerch', see McDermott 2022).

In conclusion, the music video for Viktoria Modesta's Prototype has been covered as an indepth case study and an important mediated representation of gendered LDA in pop, presented as a microcosm of her own personal history from childhood to adulthood. The nature of Modesta's LDA, being a partially-absent leg, allows for the showcasing of prosthetics with greater ease visually than if, hypothetically, her LDA involved a cyborg prosthetic digit. As Modesta is not an instrumentalist, she would not be concerned with function per se, although her prosthetic leg does affect her movement and mobility. However, due to her modelling background, her gait is that of a model on the catwalk. Her most significant work, Prototype, being placed within The X Factor (a staple of manufactured pop), should have been a platform for furthering the disability movement in pop music. However, due to privileging the superficial (style over substance), disability is fetishised suggesting that being disabled is acceptable primarily if you are aesthetically pleasing. Prototype had the potential for the creation of a futuristic, technological, utopian aesthetic of Modesta's reimagined LDA because it has been influenced by aspects of popular culture and society. This aesthetic provides musicians (and other popular culture figures) with LDA, new and exciting ways of presenting their impairment, especially through post-humanistic prosthetics.

3.5 Discussion: genre, the nature of LDA, foregrounding LDA, and the stage of life

The four popular and high-profile case studies will now be analysed in line with the key themes of the chapter. Firstly, the genre of music each operates in plays a vital role in contextualising how these musicians have presented themselves and in the media representation of their LDA. Both Tony lommi's and Black Sabbath's origins in Birmingham and the factory environment therein, are critical for the band's sound, lyrics, and aesthetic (see Poole 2007 and Lima 2015). In a similar vein, Rick Allen and Def Leppard started in the industrial city of Sheffield, thus placing them in the heavy metal subculture (McNamara 1998 and 2010). However, Def Leppard made a conscious effort to move away from their heavy metal origins as part of the 'NWOBHM' movement, to a mainstream, commercial metal band (Walser 2014, p.11-12, McIver 2014, n.pag., Earl 2009, p.43-44, and Longfellow 2002). For Jerry Garcia, the Grateful Dead were innovators in psychedelic rock and embraced all aspects of the sub-genre, such as the recreational use of psychedelic drugs in their native San Francisco, and Garcia had a carefree, experimental attitude and openness towards both his music and his LDA (Edmondson 2009, p.xii, and Jackson 2000, p.9, p.86-102).

For Viktoria Modesta, her career is defined by her LDA and her new identity with cyborg prosthetics; separating from pop music, to a collaborator as a 'bionic pop artist' (Autodesk 2017, and Dutch Digital Agencies 2019). The only true mainstream (in terms of audience reach) song Modesta has recorded is 'Prototype', which dramatises her pre-pop career life in a single music video (Farahmand 2014). The placement of this video in *The X Factor* final (Bryant and Mawer 2016, p.87), and as a vehicle to build on the momentum of the 2012 Paralympics (Channel 4 2014), has an interesting place within the four categories of pop music established by Frith (2001): 'general appeal', 'light entertainment', 'commercial imperatives', and 'personal identification' (cited in Rojek 2011, p.2-3). However, the music video follows the established tropes of pop music by sexualising women and disability in a fetishised manner. Although the representation of cyborg prosthetics with disability has the potential for change in popular music.

Secondly, the nature of becoming a musician with LDA as a pivotal moment in these musicians' lives was captured in various forms across this chapter. For example, Garcia's brother, Tiff, emphasises the moment when he brought the axe down on Jerry's finger with the word: 'wham!' (Jackson 2000, p.9). This is reminiscent of the onomatopoeia used by Tony lommi when describing the moment the factory machine crushed his fingers with the

word: 'bang!' (Lima 2015). As shown with Figure 1, the 'Fingers Bloody Fingers' animation further highlights this, thus demonstrating the power that animation can hold in visualising these seminal events (Ibid.). While Garcia's LDA was a relative non-factor in his guitar playing, Iommi's directly affected his approach to, and the way he would set up, the guitar including his prosthetic fingertips, tuning the guitar down, using light-gauge strings, and more gain used in his guitar amplifiers (Lima 2015).

For Rick Allen, the nature of his accident was particularly traumatic as he was at the height of his fame with Def Leppard. Additionally, as a drummer, losing an arm would probably have been one of the worst incidents which could have happened. It is plausible that Allen would have thought his career was over in an instant, taking away his livelihood.

Additionally, Allen had played with Def Leppard since the age of 15 (McNamara 1998 and 2010). This meant that finding an alternative career may have proved difficult (other than his advocacy side projects) (Allen 2020a, CNBC 2018, Cooper 2009, CROP Creative Media 2013, Ellis 2016, and McDermott 2022). Obviously, Allen's accident has been discussed, both biographically and narratively, with the BBC Fighting Back episode (Thomas 1992), the Vh1 Behind the Music documentary (McNamara 1998 and 2010), and in the feature film Hysteria — The Def Leppard Story (Mandel 2001). Unlike the other three case studies, Viktoria Modesta perceives her amputation as a wholly positive experience and something she had wanted for several years (Channel 4 2014). Therefore, her reinvention is based entirely on her LDA, with the application of interchangeable prosthetics at the heart of it.

As a point of reference regarding the use of prosthetics and gender, in 'Adaptation to amputation and prosthetic use' (Schaffalitzky et al., 2009), the different participants had contrasting attitudes towards prosthetics in everyday life: '[f]or male participants, functionality was important, perhaps relating to traditional social roles. For females, it appears that aesthetics is important perhaps through helping to sustain a sense of femininity' (p.71). This has parallels with my research as Iommi would only use his fingertip prosthetics to function on the guitar. Whereas, Modesta would use a variety of aesthetically-different prosthetics as fashion statements; only showing her residual limb to showcase her openness towards her own sexuality in order to subvert disability as an asexual trait. It is worth noting that Iommi's LDA is slight and therefore, it is unlikely he

would be concerned with the aesthetic nature of his prosthetics. Additionally, although Garcia and Allen did not use prosthetics, they both discovered new ways to function on their instruments of choice. Rather than utilising prosthetics to showcase their LDA aesthetically, Garcia and Allen have used the silhouettes of their LDA to highlight their absence, as a subtle form of disability consciousness (see McDermott 2022).

Stańczyk (2016) describes the use of prosthetics which aesthetically replicate the limb and/or digit it is seeking to replace as 'cosmesis' (p.71). A cosmesis 'simulates full-ability, disguises the artificial limb under clothing, and avoids situations which demand exposure...

This enables the achievement of a sense of "normalcy" or even "humanness"' (Ibid.). For lommi, based on his anecdote regarding going through customs (Iommi 2012, p.23), he was unable to avoid disguising his prostheses. Based on the fact that his LDA and the use of prosthetic fingertips helped shape heavy metal, 'normalcy' was unattainable, and although 'full-ability' was not achieved, his reimagined technique transcended any perceived limitations.

In Murray's (2009) investigation into people with absent limbs, he states that for some participants, they pride the visual of LDA and prosthetics:

[The] participants displayed their amputation, limb absence and prosthesis use as a method of defiance, resistance, and to challenge notions of disability. As such "prosthetic display" held profound personal significance and meaning to self and social identity, and was part of the politicisation of disability (p.89).

All of the case studies present their LDA in varying degrees. For lommi, his fingertips could be described as 'cosmesis' because they are flesh-like and finger-shaped. However, these prosthetics are designed more for functional reasons as lommi wanted to control his artificial fingertips on the guitar strings, despite being unable to feel the strings (lommi in Starken 1999 cited in McIver 2014, n.pag. and Cope 2010, p.31). Therefore, lommi would display his LDA sparingly. For Modesta, the utilisation of non-cosmesis, in the form of interchangeable prosthetics such as the 'spike' leg, 'light-up' leg, and 'crystallised' leg, was a stark contrast to her naked partially-absent leg in *Prototype* (Farahmand 2014), both

highlighting Modesta's prideful display of her prosthetics and her LDA. For Allen and Garcia, their LDA absences were the marking of their new visual identities. Regarding Allen, this new identity also took the form of not using a prosthetic left arm to drum; instead, he used a modified drum kit (65 Drums 2017). Garcia's guitar playing was relatively unaffected by his partially-absent middle digit (Edmondson 2009, p.xiii, Jackson 2000, p.24, Lubet 2011b, p.47, and Lesh in Sievert 2005).

A key distinction for prosthetics can be examined: 'she [Sobchack] distinguishes *her* prosthetic and *the* prosthetic: a phenomenologically lived artefact and a cultural metaphor' (Sobchack 2004, p.206 cited in Stańczyk 2016, p.71-72). Regarding Modesta, these two forms of the prosthetic come together for the *Prototype* video (Farahmand 2014) and throughout her career as a 'bionic pop artist' (Autodesk 2017, and Dutch Digital Agencies 2019). Again, for lommi, these two forms of the prosthetic combine. lommi's position as a heavy metal pioneer is based on how he created a new 'sound' built on his LDA, together with other factors such as the personal culture surrounding his hometown and his factory work (where his accident took place) (Lima 2015). Regarding Allen and Garcia (the two non-prosthetic users), their absent limb and partially-absent digit have become 'cultural metaphor(s)'. Both of them have used merchandise based on their respective absences; with the StikRick one-armed stick-figure of Rick Allen (Allen 2020b, see Figure 6), and the handprint of Jerry Garcia with a partially-absent middle digit (Jerry Garcia Family 2014b, Musictoday II 2018, see Figure 4).

With regards to the third theme of foregrounding and backgrounding LDA, Modesta has voluntarily foregrounded her LDA for her career as a solo pop act. This has also involved the collaborative reconstruction of her mediated self as a 'bionic pop artist', expanding to popular culture with collaborations involving the designs of prosthetics across many fields (Dutch Digital Agencies 2019, Hayman 2016, Modesta 2017, and IMDb 2020). Garcia, as the lead singer and guitarist of the Grateful Dead, would have been at the foreground (being the most famous member of the band). However, Garcia only presented his LDA with his distinctive handprint as merchandise in a subtle fashion (Figure 4). Regarding Allen, as a drummer, he would have been in the background visually and musically and was protected from the public during his rehabilitation (Jones 2014, McNamara 1998 and 2010, and

Thomas 1992). As Allen's accident took place at the height of his fame and deprived a drummer of one of their essential tools—an arm, Allen's LDA was inevitably going to be presented through a dramatised narrative (Mandel 2001, McNamara 1998 and 2010, and Thomas 1992). Like Garcia, Allen markets his LDA as a form of disability pride away from Def Leppard (Figure 6). It is worth noting how Allen and Garcia, whose musical peaks were long before the Internet age and the global Paralympic movement, have presented their LDA more openly in the last decade (for Garcia, this openness is through his representatives, affiliates, and family members) (Allen 2020a, CNBC 2018, CROP Creative Media 2013, Jerry Garcia Family 2014b, and Musictoday II 2018, see McDermott 2022). Finally, due to the nature of Iommi's accident and how it directly impacted the band Black Sabbath and the genre heavy metal, his LDA is paramount to guitar playing with the techniques he adopted (Lima 2015). On a personal level, there are instances of Iommi being self-conscious regarding his LDA being on view. This reticence may have been influenced by a couple of childhood accidents leaving Iommi with facial scars (Iommi 2012, p.3). As an adult, he has been able to pass his facial scars with his moustache (which he had for most of his professional career) (Ibid.).

The final theme concerns the stage of life or career when a musician's LDA occurred. Three of the case studies (Iommi, Garcia, and Modesta) were musicians with LDA before their musical careers began, allowing considerable time for adjustment and reinvention.

Conversely, for Allen, his accident took place during his time with Def Leppard, meaning he had to be musically protected by the rest of the band and his management. This protection has been through Allen's isolation in the recording studio, the inclusion of a second drummer (Status Quo's Jeff Rich) for low-key tour dates, and possibly even the new direction of the band (Jones 2014, McNamara 1998 and 2010, and Thomas 1992). Regarding Modesta, due to growing up in an oppressive environment, the presentation of Modesta as a pop artist was built on the fact that her amputation was the reinvention of herself through the incorporation of fantastical elements from film characters, concept art, and fetish clubs (Dutch Digital Agencies 2019). The social, medical, and personal trauma was prolonged before her amputation, unlike the instantaneous nature of the other case studies.

Modesta's LDA has both evolved and been resolved with concepts imagined before her amputation. Modesta used the power of the Paralympic movement to coincide with her

own message (loosely) and network with those of a similar mindset regarding the use of cyborg prosthetics in ever-changing ways.

Regarding lommi, his LDA occurred before his time in Black Sabbath. As it was his last day at his factory job and the damage to his fingers was fundamental to the creation of heavy metal, the accident has been dramatised. This is because the accident stalled lommi's progress after only a few years of guitar playing and raised doubts over whether he would be able to play the guitar again (see Lima 2015). Unlike Allen, Iommi was not in the limelight and would have been able to experiment and rehabilitate with no media scrutiny. Finally, for Garcia, it has been established that his LDA was a non-factor in most aspects of his life. Due to the fact that the end of his middle digit (on what would be his strumming/picking hand) was severed as a young child, this had little impact on his guitar playing as he had not been introduced to the instrument at this point. Instead, like Allen, Garcia's LDA representation has become his signature for personal endeavours.

To finish, the music and media representation of popular musicians with LDA is varied and complex. The investigation across the four case studies has unpacked these complexities suggesting that the personal, communal, and professional aspects generally do factor into the careers of musicians with LDA, be it holistically or sparingly. This chapter does not seek to suggest right or wrong ways of being or presenting a musician with LDA. Instead, by focusing on four famous musicians with LDA, the key themes which factor into the decisions made, both musically and visually, have been explored.

Chapter 4 – The Many Approaches to, and Ingenuity of, LDA Musicality

Because I experience the amount of pain that I do on a continual basis, I [have] always... resorted to the instrument [bass guitar] as a way to escape from that. So, I do have a pathological need.

LDA bassist Bill Clements (quoted in Williams 2013)

The more people that do this, the more people who hear about it, the more people who will think it's possible [building or modifying an adapted instrument] ... I think oftentimes, if you haven't seen something done before, you may jump to the mindset that it's too hard.

LDA pianist Valerie Thomforde (personal interview 2022)

The previous chapter focused on four popular musicians who are public figures and how they negotiated their media representation. Chapter 4 shifts in two ways: first, via a focus on grassroots, professional musicians, who are still public figures, however, their fame is less than the case studies investigated in chapter 3, and second, rather than exploring the media representation of these musicians, the examination is centred on musicians with LDA and their playing approach/relationship with their musical instrument(s). The rationale for this shift needs to be justified. When discussing high profile musicians, it is difficult to ignore their public status because this status factors into their media representation. As lesserknown musicians do not possess a 'star' status, exploring their negotiation of various media forms would detract from the focus of this chapter and the following chapter. One of the intriguing aspects investigated in the previous chapter was the playing approach utilised by three of the four musicians with LDA with their instrument. The research findings suggest that LDA musicality is potentially diverse and complex, meaning that further explanation is required. Therefore, a wider range of creative LDA instrument negotiations will be the focal point of this chapter. This involves drawing on a set of original interviews undertaken with practicing musicians with LDA and practitioners with experience of assisting such musicians.

This chapter will provide its own insights by finding common themes of LDA musicality. It will generate greater understanding behind the decisions and issues of using different methods, devices, and instruments and how improvements such as mass-production, lower costs, and reduced time and effort could make LDA musicality more efficient. However, certain issues underpinning LDA musicality will persist. Additionally, the similarities and differences of playing approaches by musicians with congenital LDA and musicians with adventitious LDA is to be explored throughout. To achieve this, the primary interview data collected from my interviewees will be introduced for an in-depth viewpoint of the perspectives of musicians with LDA and their relationship to LDA musicality. Along with the interviewees, other lesser-known musicians with LDA will be introduced. Rather than being structured on a case-by-case basis, this chapter will be signposted around the range of instrument playing provisions used by musicians with LDA, as well as the connection of popular music being inherently adaptive. Furthermore, existing sources in the form of instructional videos, articles, and secondary interviews from other notable musicians with LDA will be included to examine the commonalities. To complement this, scholarship on prosthetics, 3D-printing, occupational therapy, physical therapy, and instrument design will contextualise how methods, devices, and instruments could potentially be improved in the future. The chapter addresses my second research question: 'In what ways are prostheses; technology; musical devices; instrumental modifications; and technique important to musicians with LDA in relation to their musical and performative aims?'

This chapter is structured into four sections and a summary. First, there is identification and analysis of emerging patterns, which will recur as themes in the following sections are outlined. The second section seeks to understand how musicians with LDA have adapted to conventional, unmodified instrumentation without any prosthetic intervention such as the utilisation of unaffected limb(s) as an alternative. Third, there is an exploration into how musicians with LDA use and create prosthetic devices to facilitate their instrument playing (be it themselves or through their support network). The iterations the devices go through and the rationale for these processes will be discussed. The fourth section discusses the redesign of popular musical instruments, and the creation of new instruments to emulate conventional design for the specific requirements of different musicians with LDA. The redesign and creation ranges from relatively subtle changes such as the scordatura of the

guitar to altogether more substantial changes such as the design and construction of a one-handed saxophone. In my summary, I bring together all the findings in order to understand the scope of LDA musicality and how improvements could be made in the future, considering the links across the four sections between adapting, creating, and redesigning for musicians with LDA.

4.1 Emerging patterns within LDA musicality

To begin, I will determine how aesthetic control and expression will be defined in line with the distinction between instruments being therapy-based and performance-based (Harrison and McPherson 2017, p.270). The aesthetic control and expression of playing a musical instrument as a musician with LDA will underpin all other factors in this section. First, in order to attain aesthetic control and expression, musicians with LDA will need to connect with their instrument unless they decide to bypass their LDA. Then, the themes of trial-anderror and the individualised nature of LDA will be discussed. Following this, aesthetic control and expression can be obtained by a musician 'sonically passing' on their instrument with audiences being surprised a musician with LDA can play a musical instrument; musicians with LDA being resourceful, using a standardised approach; and/or presenting their musicality as an extension of all musicality. Musicians with LDA may sonically pass by using techniques and equipment which are befitting of their genre or emulating their favourite players. In some instances, such is the success of this sonic passing, musicians with LDA can transcend their genre boundaries with even their playing technique being replicated by able-bodied players. Furthermore, the nature of LDA can be advantageous for certain musical techniques and techniques which were previously unattainable become possible due to medical intervention.

Before continuing, I am going to clarify and provide context of what aesthetic control and expression means for LDA musicality, and how certain accessible instruments will be disqualified to narrow the focus of this study. Harrison and McPherson (2017) suggest that instrument playing has two categories: therapeutic and performance-based (p.270; Frid 2019, p.4). This raises the question of whether instrument playing should reduce the

barriers to accessing a musical instrument, allowing for aesthetic control and expression to be more free-form (category 1), or have an inherent difficulty meaning that aesthetic control and expression needs to be more precise (category 2) (Harrison and McPherson 2017, p.270-271, see Frid 2019, p.4 and Samuels 2019, p.159-160). I argue that although category 1 has value, musicians with LDA (particularly professional ones) want to be able to experience as much aesthetic control and expression as possible on their instrument of choice, encompassing category 2. The musicians with LDA studied play their musical instruments with concentrated, aesthetic control and expression, and thus would qualify for the latter category. For example, Accessible Digital Musical Instruments (ADMIs) such as the Skoog and Soundbeam would not qualify as performance-based instruments because large uncontrolled gestures can produce notes and sounds without the expected control and expression of a performance-based instrument (Samuels 2019, p.154, and Frid 2019, p.1-2). As therapeutic-based instruments do help disabled musicians have access to musical instruments, if these instruments could be reappropriated into a performance-based instrument, they would have potential value for professional musicians with LDA. As will become evident over this chapter, LDA musicality will have crossover with the therapeutic side of music-making including the fields of occupational therapy and physical therapy being beneficial to LDA musicality, and the physicality of music-making such as creating body wholeness, reducing pain, avoiding strain, and increasing comfort.

It is seemingly apparent that musicians with LDA want to have some form of aesthetic control and self-expression on their instrument(s) in order for these musicians to 'sonically achieve' in their genre of music. This aesthetic control and expression can be accomplished through three alterations to their playing approaches being: adapting their LDA to an unaltered instrument by incorporating alternative limbs and digits or bypassing their LDA entirely; using an adaptive prosthetic device to connect their LDA to their instrument or to keep their instrument stable while playing; and the alteration of a musical instrument ranging from slight changes, to a complete overhaul of an established musical instrument. In order for musicians with LDA to have aesthetic control and self-expression, they need to have command of their musical instrument. Playing the correct notes and chords may not suffice for certain musicians with LDA because the sound produced is not to their expectation, potentially due to a lack of physicality with the instrument (see Lubet 2011b,

p.167 and Téllez Vargas 2018, p.82-83). Therefore, the musicianship of musicians with adventitious LDA needs to be realised from before their LDA because these musicians usually have years of previous playing experience. This differs for musicians with congenital LDA because they need to learn how to play using alternative methods and equipment from the beginning.

The late one-handed saxophonist Neill Duncan (whose arm was amputated due to a sarcoma), explains how his musicianship for the saxophone needed to be translated for his adapted one-handed saxophone: 'People know it sounds different to my ten-fingered saxophone. People will hear it and go: 'Oh, that's you. I can hear you're back. It's so good to hear that sound again' ... My musicality has remained intact' (Duncan personal interview 2018a). It is contradictory that a listener is aware the new saxophone sounds different to a mass-produced saxophone, yet the sound is the same as before. In this instance, I believe that Duncan had been able to play his saxophone in the jazz style he had pre-LDA. However, the intricacies of his playing had been reimagined. Although Duncan acknowledges that his musicianship has changed, he realises that his musicality has been recognised by audiences to be at a similar level to before his amputation. Therefore, the preferences of the musician with LDA, chiefly the capabilities of their musical instrument in line with the genre they operate (or want to operate) in factors into LDA musicality. Drummer Jason Barnes has an amputated right forearm (due to electrocution), which has been supplanted by a prosthetic drumstick. When I asked Barnes how long it took to get to a level of musicianship he was satisfied with, he replied: 'A month... it's going to take a little bit of practise of learning how the prosthetic works' (Barnes personal interview 2019). As will become evident, even though Barnes was comfortable relatively quickly after his accident, it still took considerable time and much trial-and-error before he found a prosthetic drumstick design he was satisfied with.

It is interesting to note how before George Dennehy (who was born without arms) started playing the guitar with his feet (after the bass and cello), he felt that he might be unable to acquire the skills needed because of the multiple toes required for chording:

It took a lot of effort because... I've never really held a pick [plectrum] before... I didn't know if I'd be able to do the chords or if I'd be able to strum the whole guitar or how do I keep the guitar from shaking when I'm strumming it? How do I push down on the guitar and play the chords but the tuners [tuning pegs] ...how do they not hit the floor and get the guitar out of tune?... [Regarding the cello and the bass guitar] four-string[ed] instrument[s] and play[ing] one note at a time, maybe that's all I can do (Dennehy personal interview 2021).

Dennehy was seemingly trepidatious when approaching the guitar because he had factored in the lack of dexterity feet have for music-making versus hands. Although the bass guitar and cello have more similarities to each other when compared to the guitar, the technique of playing the guitar with feet was approached in the same way: with the guitar laying on the floor (Ibid.). Furthermore, there were a number of factors to consider including both control on, and stability of, the guitar. These factors of control and stability were also considerations for Dennehy when approaching the bass guitar and cello (Ibid.). Dennehy had very few (if any) points of reference when approaching his playing. Over the course of this chapter, what constitutes successful instrument manipulation and control for musicians with LDA will be illuminated.

In order to emphasise aesthetic control and expression, Jennifer Petry, teacher of children with limb differences and co-founder of the Cincinnati Adaptive Music Camp, is of the belief that her students should have a form of haptic connection to a stringed instrument:

The vibration of the instrument itself gives feedback and it's a really important sensory aspect of playing that you feel what you're connecting to. When you put a prosthetic device in between... your body and the instrument... your playing experience [is] less than somebody who's connecting with that instrument (Petry personal interview 2018).

One of the key aspects of aesthetic control and expression is to connect limbs and digits with the instrument directly or through a device. The musician can 'feel' the sonic qualities of their instrument, which is akin to deaf musicians such as percussionist Evelyn Glennie

emphasising the importance of vibrations in her music-making (Glennie 2019). I believe that a prosthetic device can be part of this connection to facilitate the use of residual LDA with an instrument. These devices would supplant typical limbs and digits and music-making apparatus such as drumsticks and guitar plectrums.

Andrew Tkaczyk (who has an absence in his right leg above-the-knee due to a tour bus crash) is the drummer for metalcore band, The Ghost Inside. Tkaczyk began his rehabilitation by attempting to connect his prosthetic leg to the bass drum pedal on the floor. The process began with the construction of a DIY prosthetic leg made from cheaper, household materials, taking the form of a golf putter tied with duct tape to a fire hose for stability; later extending via full consultations with experts to build a state-of-the-art prosthetic leg (Mary Free Bed Rehabilitation Hospital 2016a, 2016b, 2016c, and 2016d). However, neither of these prosthetic legs provided Tkaczyk with the haptic connection he required (SJC Custom Drums 2019). As Tkaczyk claims, the state-of-the-art prosthetic leg was too heavy for him to play fast rhythms with his thigh, and conventional bass drum control is, 'all ankle' (Ibid.). A solution to this problem was developed by Tkaczyk's father—a metal pad (replicating a bass drum pedal) was placed next to the snare drum (at thigh height) with a long, metal rod, extending to the floor, placed over the bass drum pedal. This device provided Tkaczyk instant connection with no latency (Ibid.). The process Tkaczyk went through highlights how even with the efforts of professionals attempting to build a prosthetic leg for drumming, this was not sufficient as his style of drumming requires careful limb manipulation. The pad created by a non-expert, his father, put a duplicate bass pedal adjacent to Tkaczyk's residual thigh to connect the body to the instrument (rather than distance it). The 'all ankle' aspect of bass drum control has instead been translated to 'all thigh'. Therefore, in order to connect to an instrument, there are a few methods of achieving this. These methods involve putting the residual LDA in contact with the device and/or the instrument, or bypassing LDA by connecting through alternative limbs, or adapting the instrument itself.

Another aspect which affects the methods for LDA musicality is that in order to obtain control and expression, it can take a tremendous amount of time, effort, devices, techniques, and methods undergoing a number of iterations. It has been evident that LDA

instrument playing is typically underpinned with dedicated trial-and-error through both technical and instrumental redesigns (as discussed with Rick Allen and Tony Iommi in Chapter 3). Tony Memmel, a guitarist born with an absent strumming forearm, designed his own prosthetic device by placing a guitar plectrum in his residual LDA (a space in his elbow), which was stuck down with a few cuts of adhesive tape. It took Memmel years of trial-anderror experimenting with the length of the tape, the tensions, and how to attach the tape to his arm (Memmel 2016 and Memmel personal interview 2020, and Thomforde 2016a). In a similar fashion, Andrew Tkaczyk states it had taken him three years to get relatively close to the drumming prowess he had before his accident, and although he had control, it was never going to be the same as pre-LDA (Lambgoat 2018). These examples of a musician with congenital LDA (Memmel) and one with adventitious LDA (Tkaczyk) illustrate how it can take years to get sufficient control because LDA musicality is highly nuanced. Additionally, a newly-designed instrument can be complicated to manufacture. Duncan had conversations about creating a prototype for his one-handed saxophone with instrument designer Maarten Visser over a four-year period. However, it was not until they met in person that they could collaborate and produce a more suitable instrument. This lengthy process would go on to culminate in the creation of a new saxophone in the pursuit of the one-handed saxophone to be produced in greater numbers (Duncan personal interview 2018a). These cases highlight that trial-and-error is a constant and prevailing aspect across the spectrum of LDA musicality.

Another difficulty for translating aesthetic control and expression for musicians with LDA is the individualised nature of LDA (see Lubet 2019, p.313-314). When making a comparison to musicians with LDA, it is worth bearing in mind Howe's (2016) standardised version of the 'normal performance body', which: 'usually possesses all limbs' (p.196). This is typically why solutions are individualised for LDA musicality. Musicians with LDA are unlikely to fit a uniform set of parameters for expression as they have their own musical needs. Despite Jack Thomas (whose right forearm was amputated due to a factory accident) presenting his one-armed drumming methods as universally applicable, he states that: 'I've created my own drumming identity' (Drumeo 2020). Thomas was initially provided with a Roland drum kit to play like Rick Allen under the guidance of his drum teacher (Stewart 2015). Despite bypassing an arm like Allen, the electronic drum kit did not suit Thomas, as he would return

to playing the snare with his left arm and moving the cymbals across to the left-hand side on an acoustic drum kit (Drumeo 2020). Jennifer Petry speaks of the fact that two of her armless daughters have different approaches to the cello, despite having similar LDA:

My two daughters both play with their feet and they have different bow holders...

They're [at] different angles, different lengths... have slightly different feet and...

slightly different ways of playing... [one] daughter... plays more loosely... and [the other]... with a lot more tension (Petry personal interview 2018).

Although all musicians are individuals, this individualisation is magnified for musicians with LDA as this may preclude them from getting aesthetic control and expression on their musical instrument.

The previous chapter discussed the 'visual passing' of LDA representation. In some instances, aesthetic control and expression can be achieved through 'sonic passing'. This means that musicians with LDA will adopt different methods to make their instrument playing similar aurally to that of able-bodied musicians (Vanderhamm 2020, p.280 and p.291-292). The technique of Tony Meléndez (a guitarist born without arms who plays the guitar on the floor with his feet) moves beyond sonic passing into the realms of virtuosic playing—'[i]ndeed his [Meléndez's] body is so radically different from the one presumed necessary to play guitar that... [as Meléndez puts it], "people didn't believe it... until they step in and see it, and then it became music to them"' (Ibid., p.290-291). Neill Duncan explains that due to his one-handed saxophone playing:

I can do a concert and people can be sitting 10 feet away from me and come up to me after... [and say] 'I loved your music... Hang on, you've only got one arm.' They don't see it when I'm playing... because their brain does not comprehend that the saxophone can be played by one hand (Duncan personal interview 2018a).

Although vision is not necessary to understand musical competency, it is an important way for audiences to understand how musicians with LDA play their instruments (Vanderhamm 2020, p.291). Even when presented visually with LDA, audiences are listening to the music

primarily meaning audience members can be incredulous towards LDA musicality because their expectations are for the 'normal performance body' (Howe 2016, p.196) to have produced this level of musicianship (Lubet 2011b, p.18).

In order for musicians with LDA to present their musicianship as close to Howe's 'normal performance body' as possible, they may present their creativity in a standardised manner (Shakespeare 2014, p,110 cited in Téllez Vargas 2018, p.9). This standardised approach relates to Dennehy's philosophy of his feet and legs being a direct replacement for hands and arms, hence why Dennehy plays the guitar in standard tuning: 'learning from the start... I want to play this guitar and... keep it so that I could pick up the guitar; give it to somebody with hands; and they could play it too' (Dennehy personal interview 2021). This expands to Valerie Thomforde, a pianist born with an atypical cleft hand and absent digits, who utilises a sliding technique as a crucial tool for her piano playing. Thomforde explains the rationale behind this:

Playing piano is all about illusion. Playing piano with a limb difference is all about illusion and resourcefulness. If you need to do the work of ten fingers with fewer than ten fingers, it makes sense that each finger will have to play more notes in compensation (Thomforde 2017b).

Therefore, for Dennehy, this 'resourcefulness' came in the form of using less dexterous parts of the body (his feet) with standard tunings, meaning a guitarist with the 'normal performance body' can play the same guitar instantly and without alteration. Similarly, Thomforde's 'compensation' of using fewer fingers on the piano means that the instrument remains unaltered. In Thomas' Drumeo tutorial, his philosophy of, 'work smarter; not harder' creates an illusion of two-handed drumming. A key component of this 'illusion' is Thomas' ability to fill empty spaces with extra drum hits (Drumeo 2020). To make these creative techniques more accessible, it would be useful if the rhetoric shifted away from LDA musicality as a separate entity, to LDA musicality being an extension of all musicality. The emphasis should be that all musicality requires some form of 'accommodation' (Garland-Thomson 1997, p.7 and Gibson 2015, p.119 cited in Vanderhamm 2020, p.289).

Furthermore, due to Thomas presenting his drumming methods through a mainstream drum tutorial company (Drumeo), these methods are not necessarily pitched towards drummers with LDA because this particular audience is smaller, even esoteric. By introducing his one-armed drumming technique as a universal adaptation and with Drumeo's endorsement, in a tutorial video Thomas illustrates how any drummer could utilise these methods in their conventional playing. This is evident in Thomas' speech to any drummer watching: 'whether you have two arms or one; whether you drop a stick at a show; or you want to do a drum solo while chugging a beer or a Coca-Cola for you kids out there' (quoted in Drumeo 2020). Although this narrative may seem to reduce one-armed drumming to a kind of 'party trick', if any one-armed (or indeed other LDA) drummer became aware of this tutorial, the implications for their own playing could be substantial. These techniques could either be utilised fully or as a starting point for their own methods, and, in turn, broaden the landscape of drumming as a whole.

Similar to sonic passing, musicians with LDA want to be able to produce sounds befitting of their chosen genre of music and emulate their favourite players. With Duncan, his novel style of saxophone playing is an enjoyable form of experimental musicianship. Through this adjustment, he stated that he was able to replicate and be inspired by popular musicians in the genre of jazz—in this case, Charlie Parker and Ornette Coleman (Duncan personal interview 2018a). In some cases, musicians with LDA (or limb differences) have incorporated a new, creative style which can transcend music-making in their genre and on their instrument (like lommi for heavy metal and the electric guitar). For instance, Reinhardt's two-digit soloing had been replicated by his able-bodied contemporaries (Lubet 2011b, p.46-47). Influencing a wider range of musicians with their creative and unique aesthetic control and expression can only broaden the overall musical landscape, not just LDA. In addition, these methods enhance the musical genres that musicians with LDA operate in.

When Duncan showcased his one-handed saxophone at the Strasbourg World Saxophone Congress in 2015, he discussed the fact that a dialogue could exist between jazz and classical (and all genres):

I did the Strasbourg World Saxophone Conference [Correction: Congress] and it was all classical musicians, mostly; a few jazz musicians... and they were all [fast-paced playing gesture] ... I'm nowhere near that, I can't. And even with two hands, I wasn't anyway. But I performed and the reaction was... 'Oh my God. How did you get that sound? ... What's that growl sound; that move? How did you play?' (Duncan personal interview 2018a).⁶

The unique nature of LDA musicality has the potential to transcend genre boundaries and perhaps even extend all music-making because other musicians playing the same instrument are clearly intrigued by these creative, new methods. Genres and sonic conventions will play a role in how musicians with LDA approach playing their musical instrument, and can influence or be influenced by certain players and techniques. Physical and sonic emulation can be a significant consideration for musicians with LDA.

The unusual manner in which musicians with LDA play (even if a slight deviation from the norm) will be perceived as virtuoso, as these performances are not within audience expectations. It is important to define virtuosity in this context as 'a surfeit of ability, a mastery over the human body and all its pesky deficiencies' (Howe 2010, p.144 cited in Vanderhamm 2020, p.286). There is a clear distinction between LDA musicality and conventional musicality. Audiences would say of armless guitarist Meléndez, 'I can't believe he [Meléndez] did that [play guitar] with his feet!', whereas, for a conventional guitarist, the message would be: 'I can't believe... [they] did that', leaving off the assumed 'with... [their] hands' (Vanderhamm 2020, p.292). Therefore, virtuosity can be a disbelief that a musician can play competently. For musicians with LDA, this incredulity is heightened as getting aesthetic control and expression is often more difficult. Meléndez's guitar skill is not in-built; the guitar playing requires dedication because anyone could play with their feet with a similar level of practise (Meléndez and White 1989 cited in Vanderhamm 2020, p.297). However, it is the fact that Meléndez is an armless guitarist that playing with his feet is perceived favourably because 'physical difference allows audiences to value unusual skill as legitimate, impressive, and musically meaningful' (Vanderhamm 2020, p.297).

⁶ See Dryer-Beers (1998, p.48) for the advantages of the World Saxophone Congress to saxophonists.

It is not only audiences who may be taken aback by musicians playing an instrument with their feet. Having been a student learning to play the piano with LDA, when Valerie Thomforde taught a student with LDA at the Cincinnati Adaptive Music Camp, she understood the perspective many teachers have regarding this 'virtuosic' musicality:

I taught... [one of Petry's] daughter(s)—playing piano with her toes. She played a chord and with one foot, and I had this moment where I thought: 'Wow, that was amazing'. And then I had this second moment of: 'And now I need to teach her to make it better, because she doesn't want to hear', 'Wow, that was amazing' ... [Teaching LDA students] gave me some insight on how other piano teachers see me and I get it (Thomforde personal interview 2022).

A comment intended to praise a student's efforts may be received as condescending and uninspiring. A teacher's perception of what a disabled student is capable of should be no different from that expected of one who is able-bodied. If more one-to-one music teachers were aware of the capabilities of musicians with LDA, then LDA musicality may be perceived to be more teachable and enable teachers to stretch their students on their instrument. In certain circumstances a teacher will not even be aware that they can teach a student with LDA such as when Tony Memmel approached his local guitar teacher, who believed he could not help him. Memmel did not question the teacher's reticence as he too was unaware of another guitarist who played with a partially-absent arm (Memmel personal interview 2020).

Many people perceive any form of LDA as a hindrance because LDA musicality may appear to be unfathomable. Conversely, in some contexts, LDA can in fact be advantageous. Jason 'Lefty' Williams, a blues-rock guitarist who uses a prosthetic guitar plectrum attached to his partially-absent forearm (he has had from birth), explains how guitarists have perceived his lack of a wrist as making guitar-picking easier for him:

That was because... they [conventional guitarists] move from the elbow instead of from at the wrist. And because I didn't have that secondary flexor of the wrist and

the elbow, my arm never really moved. I wasn't having to try and compensate for my forearm moving up and down, as well as my wrist changing positions. And I was really just moving from the one pivot point which made it easier to have a better picking technique (Williams personal interview 2019).

Even though Williams did not have to concern himself with navigating a wrist (a 'favourable' limitation), he still had to go through trial-and-error to find a prosthetic plectrum device to connect his residual arm with the guitar strings. Thomas speaks of the fact that his economical one-handed drumming has bettered his musicianship and timing (Day of Mourning BC 2021). Despite this improved musicianship, Thomas still went through the process of going from an electronic drum kit (Stewart 2015), to repositioning the drum kit to his left side (Drumeo 2020); with this improved timing being virtually a fortunate side-effect.

For other musicians with LDA, medical surgery has facilitated their musicality. As well as having absent arms, Meléndez was born with talipes on his left foot, which was advantageous to his guitar playing as the 'second toe was longer than the first' (Vanderhamm 2020, p298). However, the surgery to correct this was 'the only reason [Meléndez] can do minors and major sevenths' (Meléndez quoted in Ibid.). Thomforde required surgery in order to improve her digit stretching and dexterity for both everyday and musical purposes. It is fortunate that Thomforde had a relatively local, specialist surgeon who understood how to make Thomforde's affected hand more effective:

I've had 3 surgeries on my [affected] hand. When I was born, there was a lot of webbing in between my fingers and I couldn't open them very wide. And right after I was born, my parents were told about this great surgeon, Dr. Joseph Upton, who specialised in working with people with limb differences. And when I was 10 months' old, he [Upton] did ... a Z-plasty ... so I could open [my hand] wider. And then, when I was 3 and a half ... another Z-plasty surgery. And he also rotated my pinky so it was slightly apposable with my thumbs, so it was easier to pick up objects ... When I was 15, I could reach a fifth on the piano and ... very nearly reach a sixth. And Dr. Upton said to me: 'Is there anything that you would like to do with your hands that you

can't?' ... I specifically had another surgery to reach one more note on the piano. So, I can reach a sixth and I play sixths all the time (Thomforde personal interview 2022).

In some instances where the affected LDA can be incorporated or improved, the use of surgery may be necessary. Thomforde knew that surgery would allow her to play sixths on the piano, which is an integral technique to improve her piano musicianship. This highlights how even surgeons and other hospital staff could be part of the LDA music-making collaboration, if connections and communications were improved more widely. It is intriguing how these subtle physiological differences can facilitate certain techniques and make aspects of musicality easier. However, translating aesthetic control and expression can still prove difficult.

4.2 How musicians with LDA have adapted to conventional instrumentation

This section looks at musicians with LDA adapting to conventional instruments without prosthetic intervention, or modifying the instrument in any way. Many musicians with LDA will have adapted to their instrument by bypassing their LDA—in order for example to play the guitar one-handed with the fretting hand, or the drum kit by repositioning of the cymbals of the drums onto one side. Then, I will detail how armless multi-instrumentalist George Dennehy transitioned from the cello to the bass to the guitar in order to determine his mindset when developing his playing of and transitioning between these instruments. Dennehy also presents how a dedicated technique of using his toes individually was integral to his development. Following this, there is a commonality of mostly armless musicians using their feet to supplant their absent hands for everyday tasks, which translated to their music-making. To finish this section, the physicality of LDA musicality can have rehabilitative and therapeutic benefits including the occupational and physical therapy application for musicality, phantom pain relief, body completeness, strength, and comfort.

A method for adaptability applicable for musicians with LDA is playing the guitar with one hand. To utilise this method, the guitarist uses individual and pairs of digits on the fretting hand to allow what would have been played with two hands to be played by a singular

fretting hand. This economic, resourceful playing has parallels with Thomforde's description of piano playing with LDA (Thomforde 2017b). Andrés Godoy, a classical guitarist with an absent right arm, utilises the 'Tatap' technique, 'a self-taught... technique based on a series of strokes, pulls, scratches, [and] scrapes... with which he created rhythms, harmonies, [and] melodies' (Can-do Musos 2021, see Godoy 2012). Steve Dalmas, an acoustic guitarist who due to a stroke is unable to use his right hand, created his 'Dalmas method', which is applicable for LDA. The four fingers (minus the thumb) of the fretting hand are split into two pairs; the index and middle fingers tap, push, and produce chords, and the ring and pinky fingers strum and pluck the strings (Dalmas 2015). Marc Playle, a left-handed metal electric guitarist born with an absent left forearm, typically uses a prosthetic pick device for his strumming/picking hand (Playle 2008). However, he has demonstrated he can play the acoustic guitar with a one-handed 'pseudo-fingerstyle' (Ibid., 2009). Bill Clements (who lost his right arm in a factory accident) plays the bass guitar with one hand and bypasses his dayto-day prosthetic right arm musically (see Williams 2013). Clements did not consider using a prosthetic: 'What I was developing with my left hand was so far out and advanced of anything I could possibly cobble together using a prosthetic. It would be like taking two steps backward[s]' (quoted in Ibid.). He decided that he would adopt a method used for a different fretted string instrument, the Chapman Stick (Liebman 2012). The Chapman Stick is similar to the guitar. However, a key difference is the Chapman Stick is fretted typically by two hands on the strings to produce sound, rather than utilising both a picking hand and a fretting hand (Stick Enterprises 2021). Clements would apply this knowledge to the bass guitar to strike his left hand on the fretboard in an energetic manner (Williams 2013 and Lubet 2019, p.315).

The above examples provide evidence that the fretting hand can be as effective as playing with two hands on the guitar due to the dexterity of fingers. In some instances, the picking hand may be too difficult or unnecessary to incorporate in a musician's guitar or bass playing. The versatility of the guitar and bass guitar allows musicians with (or choosing to use) one hand to adapt without making any significant alterations to the instruments. This adaptability is reminiscent of armless guitarists using their feet with different tunings, which is a slight standardised change utilised by most guitarists. For guitarists and bassists utilising their fretting hand, it is sensible and logical as four fingers can fret the strings or pluck them

(the thumb is placed around the back of the guitar neck for stability). Guitarists with adventitious and congenital LDA (and beyond) would be able to utilise these techniques through training. As will be explained later, the guitar and bass guitar could be described as 'prototypes' for universal design, whereas, the creation of a one-handed saxophone with wholesale mechanical changes is not a viable prototype (Duncan personal interview 2018a).

Another adaptable musical instrument is the drum kit. Jack Thomas, a mainly hardcore punk drummer and an above-the-elbow right arm amputee due to a factory accident, speaks about the numerous ergonomic and economic technique alterations he made to the drums to suit playing with his LDA. In essence, adapted one-armed drumming with no assistive technology. These alterations include: a sweeping technique (hitting as many drums as possible in a single motion); a technique taught to him called the 'hot stove' (hitting the snare and pulling the stick back, which is analogous to pulling a hand away from a hot stove); the 'cross-stick' technique (holding the drumstick in the middle as a pivot point for one side to hit the snare and the other to hit the hi-hat); the light cymbal accent (similar to the 'hot stove' technique by playing the cymbal another time lightly); and the ergonomic repositioning of all the cymbals to the left-hand side of the drum kit to allow Thomas to favour his left side (Drumeo 2020). Thomas' utilisation of his weaker (left) hand has been addressed:

I don't have a choice. I can't afford to have a weak hand. I have to work extra hard with my technique. The thing that you do is practise; you develop; you gain those skills by putting in the work (quoted in Ibid., see Dokumaci 2023, p.7).

Thomas took his experiences from his years of pre-LDA drumming and extrapolated this knowledge for one-armed drumming. Thomas' economical playing is able to 'fill in the gaps' his right arm used to play. Additionally, the ergonomic rearranging of the drum kit to complement his new playing style, utilises the 'rearrangement' of Thomas' muscle memory and training. If those with congenital LDA could utilise one-armed drumming from the beginning, these drummers could learn such techniques in line with the rest of their training. Therefore, access to this knowledge would probably reduce the trial-and-error Thomas had to endure when relearning. With Thomas' relearning of the drums, it is evident

that he felt that adapting to a conventional drum kit was more comfortable and suitable for him over attempting to use a prosthetic right forearm or drumstick to play, which is potentially due to pain and straining.

The musicians with LDA examined in this section thus far have involved adapting to one instrument. When interviewing armless multi-instrumentalist George Dennehy, the transitioning from the cello to the bass and the bass to the guitar were discussed. Dennehy's first instrument, the cello, would have been where he honed his craft:

It [the cello] was a lot of work and it was really challenging... Using my feet for just daily things... came naturally... But learning an instrument... you learn it and you have to practise and you have to teach your muscles... I was doing that with my toes... I think it maybe took two years I would say until I felt really comfortable (Dennehy personal interview 2021).

His next instrument, bass guitar, was a smoother transition because the similarities between the cello and the bass guitar outweighed the differences:

There's no frets (sic) on a cello to frets on a bass and I've been so used to holding a bow on a cello and here I am without a bow... where you're plucking instead of a bow; plucking is basically finger picking... When I learned to play bass, I just told myself: 'Okay, I'm basically plucking this instrument' (Ibid.).

As mentioned previously, his third instrument, guitar, was more difficult to transition to. Although the guitar is a stringed instrument, Dennehy felt that the techniques and modifications were initially difficult: 'There's so much going on with that... [the guitar] I had that mentality and that discipline to keep figuring it out and here I am today; still learning and still practising and still teaching myself' (Ibid.).

Despite the difficulties of continual adapting and focused practising, as a musician with congenital LDA, Dennehy would have found it easier to play with his feet from the early stages of his instrument-playing development. This differs to a musician with adventitious

LDA having years of practise playing an instrument with their hands, and subsequently, relearning their instrument playing knowledge. Dennehy recalls the amount of effort and collaboration needed to play the cello being laborious:

I was seven... when I had [cello] lessons, we [Petry and Dennehy] [would] spend the whole hour not even playing the cello. She would just hold my toes down on the ground and tell me to just lift all toes except one... that's not being held down; ... it was just like an exercise. And I would do that over and over again for weeks... until I could just do that myself... And that translated really well into playing the cello, and having the dexterity to play the notes and move my toes fast if I need to (Ibid.).

These exercises are logical because an armless musician using individual toes has parallels with conventional musicians using individual fingers. Typically, people use individual fingers for a variety of everyday tasks such as typing and writing with a pen; a task akin to holding a guitar plectrum. Therefore, it could be surmised that everyday tasks are a 'prototype' for instrument playing and need to have dedicated practise behind them for successful navigation. Armless musicians also use their feet for everyday tasks and have utilised that muscle memory and development to learn to play a musical instrument. A question may arise for musicians with absent arms: have they considered using prosthetic arms? For Dennehy, he tried using prosthetics but found it more efficient to use his feet (WCVE-TV 2013). Meléndez used prosthetics until the age of ten, when he decided to use his feet instead, as he felt his feet were more effective and the prosthetics were 'uncomfortable' (Meléndez 2021). Armless musicians deciding not to use prosthetics is logical because a full arm has many points of articulation from the shoulders, elbows, and wrists, to more intricate actions of grip and digit manipulation. Meléndez and Dennehy came to the realisation that using prosthetics in everyday life and music was not feasible for them, as they could not get comfort or control, even with practise.

As Vanderhamm (2020) states: 'guitar necks seem to disable those without arms or hands—unless, of course, they can learn to play with their feet' (p.288). It is apparent that musical instruments and everyday objects do not disable people with feet, if they can adapt or use adaptive devices creatively (see Dokumaci 2023, p.5-7, and p.9). The dualistic command of

everyday tasks and music involves musicians with LDA (particularly armless musicians) having control of their body and their environment (Vanderhamm 2020, p.287-288). Dokumaci (2023) has described the phenomenon of everyday negotiations and coined the term 'activist affordances' (p.5). Being able to navigate tasks in day-to-day life highlights personal independence (Garland-Thomson 2009, p.119 and p.132-133). I asked Dennehy how the everyday tasks translated to his instrument playing and vice versa:

I think one thing that definitely translated from playing instruments is... typing; typing on a computer; typing on my phone most of the time. Just out of preference, I usually only type with my big toes anyways... I can easily just use those two toes... I would say definitely writing too; ...I can pick up things... larger things like big cups or big books... Being able to hit those notes on a cello—we did a lot of stretches as well—and I think that definitely translated into everyday things too (Dennehy personal interview 2021).

Although Dennehy has command of playing instruments and performing everyday tasks, this is not to say that armless musicians will ever have full control but they have as good a grasp as possible (see Meléndez interviewed by Vanderhamm 2020, p.296). On some occasions, everyday tasks can be more challenging than playing a musical instrument. Dan Caro (whose fingers are absent due to a house fire as a toddler) claims that tying his shoelaces was a far more difficult task for him than drumming (Dawson 2005 p.125 and PBS 2013), due to the fact that tying shoelaces requires fine motor dexterity versus the gross motor dexterity of drumming. Audiences may be unable to appreciate the use of feet for everyday tasks because audiences assume that an armless musician only has the ability to play a musical instrument with their feet. Despite Meléndez playing the guitar with his feet, a concert organiser was most taken back by how Meléndez texted on a phone with his feet before a concert, and another colleague thought Meléndez could not tune his own guitar (Vanderhamm 2020, p.284 and p.296). Most audiences will not be aware (or interested in) how musicians with LDA perform everyday tasks because the connection is unclear. When a musician without LDA performs everyday tasks with their hands, it is unremarkable and mundane. However, if the correlation of how musicians with LDA perform everyday tasks

and play a musical instrument can be established, this will provide audiences with the context of how these activities are achieved (see Dokumaci 2023, p.27).

Although everyday activities can be carried out using feet, there is no set way of performing these tasks. This phenomenon has parallels with the individualised nature of LDA musicality because there are numerous methods for playing a musical instrument, as well as carrying out everyday tasks. Dennehy states that he and his armless brother have each chosen a contrasting method for buttoning their shirts:

[My brother will] button his shirt after he puts it on, so it's already on him and he's buttoning it with one foot. I will button my shirt on the floor before I put it on... I'm always happy to give my advice and what I did as... a baseline (Dennehy personal interview 2021).

In the music video for the 'Lefty Williams Band' song *Let It Roll On* (2014), as well as playing the guitar with his adaptive plectrum device, Williams is shown performing a number of everyday tasks including tying his shoelaces with one hand (Lefty Williams Band 2014). Williams decided to make a separate video of him tying shoelaces (Williams 2014). I asked Williams for the reasoning behind the inclusion of everyday tasks and the separate video:

It [the music video] really wasn't about showing that I could tie my shoes as a one-handed person... The point of that [music video] was what it was like to be on tour... And then I started getting inquiries, 'we were trying to teach our kid... How do you do that [tie your shoelaces]? Because it's not long enough of a clip to really see what you're doing'. And that's what... led me to do the [separate] video... because somebody specifically asked (Williams personal interview 2019).

This advice could be used for LDA musicality because there is a correlation between everyday tasks and music. Furthermore, these statements highlight that Dennehy and Williams are willing to share their methods for everyday tasks, if requested.

Numerous armless musicians have had documentaries and news segments displaying the use of their feet for an array of everyday tasks to complement their instrument playing, including George Dennehy (Baas 2012, WCVE-TV 2013, and WDZ Film 2016); Mark Goffeney (Schlatter 2017, Caters TV 2016, Harris and Gonzales 2015, and Quinn 2003); Tony Meléndez (Guevara 2000), Alvin Law (Law 2015), and Johnatha Bastos (although Bastos has partially-absent arms and occasionally uses his arms for everyday tasks over his feet, see Callil and Moraes 2013).

Figure 9 – Armless multi-instrumentalist Mark Goffeney has combined both everyday and music for his album cover, *Big Toe* (2001).

The music and everyday connection has been recognised by Mark Goffeney through a different form of visual media, album artwork (Figure 9). The album cover displays a pair of feet on the steering wheel driving down a road in the shape of a guitar fretboard. It is not only musicians with congenital LDA who have been displayed carrying out everyday tasks and music together in a single documentary. In the BBC television programme, *Fighting Back*, Rick Allen is shown using his left foot as a direct replacement for his absent left arm: most notably in the kitchen preparing food (Thomas 1992). The comparison of everyday tasks and playing a musical instrument demonstrates the influence the two categories have on one another, as well as the skill required for both. However, the inclusion of everyday

tasks may be perceived as a 'shallow gimmick' (Meléndez and White 1989, p.3 cited in Vanderhamm 2020, p.297) for the use of feet in place of hands (see Callil and Moraes 2013, where an able-bodied reporter has her arms tied to her body to replicate Bastos performing everyday tasks with his feet and partially-absent arms).

With the parallels of instrument playing and carrying out everyday tasks, the methods utilised are dependent on the physical specificity of the individual. Based on musicians having to find replacements for absent hands, most apply their methods for accomplishing everyday tasks into their instrument playing. The main exceptions are Jason 'Lefty' Williams and Johnatha Bastos. Williams uses his partially-absent forearm for everyday tasks and a prosthetic device for playing the guitar. This difference is probably due to the fact that a plectrum strapped to his residual forearm is preferable to gripping a plectrum over a prolonged period of time. Whereas, tying shoelaces and other everyday tasks are much less time-consuming. Bastos mostly uses his feet for everyday tasks and musical instruments. However, on occasion, Bastos does use his partially-absent arms for holding drumsticks and holding objects. These decisions are logical because Bastos tends to use his feet for more dexterous tasks and everyday tasks below waist height. Whereas, tasks above waist height and holding drumsticks often requires less grip and less dexterity, hence why Bastos is able to incorporate the use of his partially-absent arms.

Another connection which can draw together the physicality of everyday life and playing a musical instrument is the utilisation of occupational and physical therapy. Jennifer Petry has used her sister's experience in occupational therapy for her own teaching: 'I'm pretty well-versed with the OT side because my family is ... full of doctors. My sister's an OT and I will get free advice from them ... My sister will come work with my children' (Petry personal interview 2018). It is clear that occupational therapy is not only valuable to music but can translate to other walks of life, as Petry recalls with an interaction with a parent whose child was learning to play a musical instrument. The action of music-making:

was good for ... the development of that [affected] hand ... She [a student with limb difference(s)] was more willing to use that hand to do things because she was using it on her instrument. And I've heard that a couple of different times. Parents have

come back to me and said: 'I don't even care about the music anymore. What this is doing to my child's occupational therapy is wonderful' (Ibid.).

For an occupational therapist or physical therapist who is seeking an activity to improve LDA function, the playing of a musical instrument would undoubtedly be one of the most beneficial, as the task requires the dexterity of limbs and digits. Another form of physical therapy is the translation of everyday activities to musical instrument playing. One particular example is George Dennehy mastering his everyday environments and thus translating to music and vice versa (Dennehy personal interview 2021).

Regarding occupational and physical (music) therapists, their value extends beyond collaboration with disabled students for therapy into instrumental performance for musicians with LDA. This includes phantom pain relief, body completeness, and strength for playing a musical instrument (de Jong et al. 2021, p.375, p.377, p.382, Paul and Ramsey 2000, p.111-112, and Woldendorp and van Gils 2012, p.231-232). The act of playing a musical instrument can have therapeutic and rehabilitative benefits for a musician with LDA, particularly those with phantom limb(s) pain. Bill Clements, who frets the bass one-handed (bypassing his partially-absent right arm), expresses the fact that he is dependent on playing the bass:

Because I experience the amount of pain that I do on a continual basis, I [have] always... resorted to the instrument [bass guitar] as a way to escape from that. So, I do have a pathological need. In fact, I feel nervous because ... I don't have a bass in my hand right now... The physical act of doing something ... is really the only thing that is effective in combating my situation (quoted in Williams 2013).

Clements had dealt with the trauma of losing part of his arm by allowing his creative output to act as an instrumental prosthesis (see Lubet 2013). Neill Duncan explains that his one-handed saxophone makes him feel as if he has a left arm: 'What the horn [saxophone] has done for me is it's made me feel complete again. I don't wear a prosthesis; this is my prosthesis [points to saxophone]. When I'm playing the horn, I feel complete' (Duncan

2018b, see Manderson and Peake 2005, p.239 regarding the notion of wholeness, and Lubet 2013). Duncan speaks of the sensation of his partially-absent phantom left arm:

I have... serious phantom pain. That's another thing that can make me feel whole because it still feels like I have an arm. It's there; it's sore; and it's against my chest; and it's paralysed; and it's aching; and it's horrible; but it's an arm. So, I still feel like a two-armed [player] ...It wasn't until later that I started noticing that, 'Oh, every time I play the saxophone, my phantom pain disappears' ... Because it comes and goes ... But I know that even in one of the worse moments, if I play, it disappears (Duncan personal interview 2018a).

Duncan also states that when he plays the saxophone, his phantom digits actually move in time with his playing:

When I'm playing the horn, my left [phantom] fingers started moving ... and I can feel them. They're dancing ... because my brain is going up to 25-30 years of using my left hand on the instrument. When my brain hears the sounds and when I go for certain sounds, that starts moving the fingers (Duncan 2018b).

Based on Clements' and Duncan's experiences, it appears that for a musician with adventitious LDA, the playing of a musical instrument can give a sense of body completeness, be a form of phantom pain relief, and improve mental wellbeing. For congenital LDA, there will be no phantom pain experienced. Instead, comfort and physicality will be emphasised for aesthetic control and expression. With a lack of prior instrument knowledge, the learning of the instrument will require a greater level of unexplored application. This is not to say that the musicians need to be virtuosos, however, improvement in the developing stages of their training is for the best. Furthermore, musicians with adventitious LDA have a baseline for their previous instrument playing. This means that these musicians will compare and contrast to understand where their new musicianship fits within their profession and their preferred genre. In most instances, this baseline is unattainable with a reimagination of their musicianship required instead.

Using occupational therapy and physical therapy with music and disability may be beneficial. It could be argued that music teachers, musicians, and manufacturers can assume the role of an OT and PT, with instrument playing being a key factor in this process. For example, Bill Clements and Neill Duncan have each explained how playing a musical instrument benefited their phantom pain and overall mindset (Duncan personal interview 2018a and 2018b, and Williams 2013). Petry and Thomforde both understand that OT and PT has been helpful to children with LDA (Petry personal interview 2018 and Thomforde personal interview 2022). If music teachers, OTs, and PTs could communicate with one another to help their students and clients, this may have positive implications for all parties. Beyond OT and PT, Thomforde used medical intervention to improve the mobility of her cleft hand for both daily life activities and to improve her reach on the piano (Thomforde personal interview 2022).

4.3 How musicians with LDA have incorporated an 'adaptive prosthetic device'

I begin this section with a definition of 'adaptive prosthetic device' for music-making in order to understand how adaptive prosthetic devices differ from adapting to an instrument, and redesigning an instrument. Adaptive prosthetic devices are a broad mixture of prostheses and orthoses to restore function and support parts with limited function (Ott 2002, p.21, p.32-33). Musicians with LDA have incorporated commercially-available devices (both musical and everyday items) to facilitate their music-making. Also, musicians with LDA (and disabled musicians) have been willing to share their devices for music-making with any musician or person who is willing (or even unwilling) to utilise the devices. Then, I will highlight an example of how an 'adaptive prosthetic device' can be teamed with physical therapy. Further inexpensive devices will be presented, which required engineering and may have included the support of 'non-experts' as opposed to the perceived 'experts'. To contrast this, the use of expensive devices in both everyday life and in music will be examined, which may involve trial-and-error, individualisation, and compromise in order to find the technology desired, for the betterment of a field such as prosthetics. Even when presented with alternatives, which are cheaper, possibly free, musicians may choose the expensive option. Even cheaper devices can still go through the trial-and-error process and

many iterations, due to the individualised nature of LDA, yet can be ingenious. Finally, the issue of keeping an instrument stable can present itself to a musician with LDA, which needs to be navigated.

It is worth making the distinction between a 'prosthetic limb' which may be used solely for functional purposes and a 'prosthetic device' for aesthetic control and expression on a musical instrument. For example, a prosthetic arm may be used for picking up objects, whereas, a prosthetic device would be geared towards fine motor skills, such as the role hands and fingers would typically play on a stringed instrument. Accordingly, it is important to define what is meant by an 'adapted prosthetic device'. For the purposes of this chapter, this type of prosthetic device will be defined as a broad mixture of prostheses and orthoses: 'prosthetics as external appliances used to... restore function... Orthoses generally do not replace body parts, but instead support parts that have limited function' (Ott 2002, p.32-33, see Ibid., p.21). An 'adapted prosthetic device' would need to, 'restore [or provide] function' and, 'support parts that have limited function', depending on the nature of a musician's LDA. Aesthetic control and expression involving prosthetics will require 'trial-and-error', as factors such as comfort, stability, joint manipulation, and strength need to be considered: 'In the history of technology and medicine, the human body is a design and engineering project' (Ibid., p.17). Beyond ergonomic factors, prosthetics come in an array of forms, 'simple or complex, homemade or mass-produced, mechanically engineered or high-tech' (Ibid., p.16). Prosthetics which are not made from state-of-the-art equipment, can instead be made from cheaper materials such as: 'leather, wood... and rubber were used to approximate the mechanical behaviour of joints, sockets, stumps, and muscles' (Ibid., p.31). These lower-cost options are better for experimentation because the trial-and-error process would be less expensive for the individualised nature of LDA.

It is worth exploring the viability of mass-produced devices, which can be applied to LDA musicality and how sharing these devices may be helpful. A number of musicians with LDA utilise commercially-available devices to aid their musicality. As noted previously, Clements uses (as well as promotes) a cheap, commercially-available device called FretWraps (Lubet 2019, p.315 and p.317, and Gruv Gear 2021). In promoting FretWraps, Clements highlights

the benefits of the device for himself and the fact that the device can be used by all musicians using a fretted, string instrument:

What this does for me is acts as a dampener to reduce unwanted string noise, which would positively run amok if there was not something tied around there [the bass guitar neck]. In the past, I've used all sorts of things—hair ties, socks, underwear—any number of things. But, at any rate, this is specifically designed for just that purpose. Someone who's playing with two hands can find a lot of applications for it too (quoted in Gruv Gear 2012).

Clements found that the best solution for his 'sound' (where he bypasses his LDA to fret the bass guitar one-handed) was a device designed for its very purpose rather than repurposing a DIY solution, which is rare. Having gone through the 'trial-and-error' process, the FretWraps allows Clements to 'control' his aggressive style. Notwithstanding any commercial self-interest, it is intriguing that despite Clements stressing the importance of this device to his own bass playing, he applies the FretWraps to any musician playing a fretted, string instrument. The lens shifts from the individualised nature of LDA to the universal applications and virtues of the FretWraps; akin to the guitar plectrum becoming a universally accepted tool for the guitar and bass guitar (and other fretted string instruments) over time.

Memmel endorses the use of Gorilla Tape for music-making (Lubet 2019, p.315, and Memmel 2013). In this instance, a company's product is being reappropriated away from everyday purposes into music. Memmel advocates for Gorilla Tape as a prototype for musicians with limb differences: 'I think it's a really good solution, and it's inexpensive, and it's something that students that I work with can go to the store and get today. They don't have to wait and go for [prosthetic] fittings' (Memmel personal interview 2020). The positives of Gorilla Tape are that it can be a cost-effective solution and is easily available. This could potentially reduce the trial-and-error process because, as Memmel highlights, a musician with LDA may not need to visit a hospital for prosthetic fittings (Ibid.). Memmel appreciates that, despite the advantages of Gorilla Tape due to its low-cost, it cannot be used universally:

I can be at a conference for people with limb differences. And I'll have a line of 30 people who come to sit at my chair with me to try guitar for the first time. And they have such a wide array of different hands and arms (Ibid.).

The individualised nature of LDA highlights the difficulty of finding a solution which can translate like-for-like between one musician with LDA to the next. Despite this individualisation, various musicians with LDA or those working with them are more than willing to share their device designs with anyone who needs them. Here are the accounts of drummer Jason Barnes and David Segal, co-founder of Can-Do Musos and a disabled drummer, explaining that disabled musicians have requested their designs. Barnes remarks: 'all the kids [who] have reached out to me ... have asked me how my prosthetic is made ... I'd give anyone the whole designs of everything and how to make it' (Barnes personal interview 2019). Segal states: 'I've also had people where they've copied my device and had their parent make one for them or ... the doctor who made this one for me; I give them ... [the doctor's] phone number and they've made it' (Segal personal interview 2020).

Conversely, Jason 'Lefty' Williams wanted to share his ideas with prosthetic companies and received little to no encouragement:

I did try to team up with a couple of different doctors and Hanger prosthetics [a provider of prosthetic and orthotic care] here in Atlanta and they were honestly... completely indifferent... basically, ...for lack of a better term, ghosted. I would reach out and discuss the idea with them and then just never hear from them again; never get responses to my follow-up calls. I don't want to make it seem like I tried a bunch of different places... two different doctors... And my sole ambition in that, when I was trying it was to try and make something that was a little more readily-available to the general public (Williams personal interview 2019).

These examples suggest that regardless of whether useful parties who could better LDA musicality and disabled musicality are interested in the ideas, concepts, and devices of musicians with LDA, the musicians themselves are more than willing to share them.

An 'adapted prosthetic device' can also be teamed with physical therapy and muscle development. Holding the drumsticks would prove to be challenging for Dan Caro. His left side was easier because Caro had a reconstructed left thumb he could hold a drumstick with; however, his right hand had no grip (Dawson 2005, p.125). Therefore, Caro had to create a device for his right hand comprising of a 'wristband with a rubber band around it, which simulates the fulcrum between the thumb and index finger of matched grip' (Ibid., see KTVK 2012, and WFXT 2012 for visual stimuli). The device was limited yet satisfactory enough for Caro's needs. Even though Caro could grip the stick in what remains of his left hand and his reconstructed thumb, he did not have the strength to use this hand for drumming because the act of drumming is a 'focused muscular action' and the stick was difficult to control (Dawson 2005, p.125). Caro realised that the strength and grip he was developing in his affected arms meant that he could compromise on having a device which was not ideal, as the 'trial-and-error' process had allowed him to reach this conclusion.

Jason 'Lefty' Williams manufactured his own adapted prosthetic plectrum device. Despite the device needing a fair amount of engineering, the overall cost was relatively low:

I think a pick cost me about 10 bucks to make... There's probably 20-30 dollars' worth of initial investment of tools... I use a pair of lineman's pliers to hold the pick and warm it up so that I can bend it. The linesman's pliers are probably 30 bucks... So, probably about 50-60 dollars' worth of tools... and the materials involved in making the pick, probably no more than 20-25 dollars (Williams personal interview 2019).⁷

In a similar vein to Williams being willing to share how he tied his shoelaces with one hand, he formerly shared the process of how he built his plectrum device on his website (Ibid., see Lubet 2019, p.315-316).

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⁷ Upon review, Williams stated that the device was called 'lineman's pliers'. Previously, I thought Williams had said 'lineman's files' (see Ibid.).

There are instances where practitioners are unable to assist musicians with LDA meaning that the musician usually has to take it upon themselves to find what methods or devices work for them. If a musician with LDA can be supported, the assistance may in fact be from a person closely related to the musician with LDA in the creation of an inexpensive, adapted prosthetic device. Andrew Tkaczyk collaborated with the Mary Free Bed Rehabilitation Hospital whose goal was to create a state-of-the-art prosthetic right leg to connect his right thigh to the bass drum pedal (Mary Free Bed Rehabilitation Hospital 2016b, and 2016c). However, this lengthy process did not achieve what Tkaczyk needed musically (SJC Custom Drums 2019). It was, in fact, a non-expert (in terms of prosthetic design for musical purposes) who constructed the solution Tkaczyk needed:

My Dad had this idea [for a prosthetic] from the start. And it was to make a device... playing with just my limb—nothing on it—with a pedal that basically came up to where my snare drum is, that would be connected to the kick drum pedal... and we're always adjusting (quoted in Ibid.).

This case further cements that the trial-and-error process may be necessary to realise the requirements of musicians with LDA. Although this solution is not perfect, it has provided Tkaczyk better aesthetic control and expression versus a state-of-the-art prosthetic leg created by a medical institution specialising in somatic rehabilitation.

When Dennehy wanted to stabilise the neck of his bass guitar on the floor, it was a bandmate (at the time) who devised a solution:

I'm playing wrong notes because my bass is out of tune and that was probably frustrating [for the other band members] ... So, one of the band members... put together this wooden block... Before they helped... I would just use my shoe... and put it under my bass and hold it up. I thankfully didn't really go through many materials before using what I use now (Dennehy personal interview 2021).

Additionally, Williams described the materials he experimented with and how it was a bandmate's family member who came up with the best solution for attaching the plectrum to his forearm:

I was playing in a band in the mid-90s... I forgot my pick at home... The second guitar player in the band got it in his head that I should have multiple back-up copies so that I would never do that again. And he talked to his Mom about it; his Mom was really good at sewing... I think she wound up making me three or four different picks... She was the one that came up with the idea for using rivets to attach it [the plectrum] to the strapping and that has been what I've used ever since (Williams personal interview 2019).

The above examples support the notion that 'non-experts' may be able to provide equal or even better engineering solutions over perceived 'experts'. This may be due to the fact that most device designers do not have any points of reference to learn from. Based on the cheap, DIY nature of these devices, it is understandable how people within a musician with LDA's social circle are willing to help. The issue for various organisations and experts is that they do not always have consistent, face-to-face, and personal communications with the musician with LDA. For instance, appointments at a hospital would need to be organised and may be less of a priority for the medical institution over day-to-day accidents.

Most 'adapted prosthetic devices' are made of easily-accessible, cheaper, DIY materials making the customisation of numerous versions of a 'device' viable. However, expensive prosthetics can be applied in everyday settings. An integral development for prosthetics was the birth of myoelectric technology, although it is unlikely that myoelectric prosthetics will be mass-produced:

Myoelectric activation occurs when the prosthesis wearer contracts a designated muscle. The muscle signal is amplified and then relayed to a battery control, which in turns operates the hook or hand. Myoelectric limbs have yet to reach an engineering level that makes them commercially viable on a large scale (Ott 2002, p.20).

Although this statement was made more than twenty years ago, it remains the case that the cost of these types of prosthetics is prohibitive. In a similar vein to the music and everyday connection established in the previous section, independence can be gained by carrying out everyday tasks with prosthetic intervention. Drummer Jason Barnes uses three separate prosthetic devices for everyday tasks. Barnes discusses the differences of his Bebionic hand and his myoelectric hook: 'My Bebionic [hand] is pretty much for just daily chores and activities... Anything more strenuous... [such as] working out in the yard or construction... I [Barnes] would use my myoelectric hook, which is basically like a body-powered hook' (Barnes personal interview 2019). Barnes has two prosthetics hooks, one body-powered and the other myoelectric, and explains the differences:

A myoelectric hook... has a very wide level of strength settings. And I also have an electronic wrist rotator... The body-powered hook essentially does the same thing but everything's manual... The way the strength settings work on a body-powered prosthetic... [is] a rubber-band system (Ibid.).

Myoelectric technology provides ingenious solutions to carrying out tasks. However, due to the complex nature of LDA, there is unlikely to be a one-size-fits-all myoelectric prosthetic. Barnes also decided that he wanted to utilise more expensive prosthetics in the pursuit of a prosthetic drumstick he could control with EMG (electromyography) technology (Ibid. and Maderer 2014). His original, cheaper prosthetic drumstick was not sufficient for the aesthetic control and expression he wanted:

I just used [the] basic laws of mechanics and some leverage and a spring. And it [the prosthetic drumstick] worked but I couldn't really play any really fast rudiments or play like jazz 'swing'. I couldn't play... at a certain speed because I was limited on how that spring and everything bounced. So, the idea was to develop a one-stick version that would use EMG [electromyography] ...Then I could essentially flex my muscle and then the stick would act as my fingers and wrist. Then that's what we [Gil Weinberg and Barnes] developed with the two-stick version, but it has two sticks and a bunch of other unnecessary technology (Barnes personal interview 2019).

Therefore, in order to get the EMG technology to facilitate control of the prosthetic drumstick, Barnes had to collaborate with the Georgia Tech Robotics Department, along with obtaining funding from the National Science Foundation (Maderer 2014). To fulfil the wants of all three parties, Barnes had to compromise by getting a two-stick prosthetic—one stick with EMG technology, and the second with robotic technology which would react to Barnes' playing. The second stick was for the vested interest of Georgia Tech and The National Science Foundation (Ibid.), yet the second stick was perceived as 'unnecessary' by Barnes (Barnes personal interview 2019). Barnes has expressed his feelings on the two-stick prosthetic: 'There's definitely certain people that are maybe worried that we're trying to make robots take over music or it might be cheating because it has two sticks, which is again my reasoning behind the one stick' (Ibid.). The original prosthetic drumstick did not provide him with the necessary control that he needed for certain techniques. Therefore, in the pursuit of this aesthetic control and expression, Barnes was willing to yield by using expensive and superfluous prosthetics, as well as collaborating with organisations in order to get the funding and expertise he would otherwise lack, for the EMG technology he knew he needed.

Barnes also joined forces with Georgia Tech on another project: the incorporation of a 3D-printed robotic hand with individual robotic fingers controlled by Barnes' forearm in order to play a piano keyboard (Maderer 2017). Barnes explains the pros and cons of the robotic hand:

That [the robotic hand] was still extremely experimental technology because no one has... had success in using an ultrasound sensor to operate five individual fingers. Everything was very slow. It [the hand] was extremely accurate but I could only do one finger at a time. We [Barnes and Georgia Tech] weren't... [far] enough along to make it [the hand] do gestures or chords. And then again, it... [the hand] has a second of latency... But we sparked the idea in a lot of bigger prosthetic companies now (Barnes personal interview 2019).

This experience can be related to Tkaczyk discussing the latency of playing the bass drum with his prosthetic leg versus a pad placed by his thigh (SJC Custom Drums 2019). Although

having control on an instrument is important, this control needs to be combined with speed because there needs to be as little latency as possible between the 'adapted prosthetic device' or limb/digit and the instrument.

With Thomas and Allen, they primarily adapted to, and rearranged, the drum kit. Therefore, this raises a question: why didn't Barnes do the same? He decided that using a prosthetic drumstick controlled by his forearm was preferable: 'It's essentially just my hand [that is absent] and I liked the idea of prosthetics or technology... more so than just adapting' (Barnes personal interview 2019). Barnes pursued the more expensive prosthetic avenue because he wanted to acquire the technology he needed for controlling the drumstick using his residual right forearm. Barnes is also an advocate for helping people with prosthetic technology and the betterment of the field as a whole, as he has acknowledged with the robotic hand for piano playing (Ibid.). Therefore, it is interesting to postulate that if Barnes had known about Thomas' one-handed drumming techniques beforehand (which could easily bypass his residual right forearm), would Barnes have decided to save a significant amount of money by adapting, rather than chasing funding for a prosthetic drumstick? The evidence suggests that even if Barnes had been presented with the methods Thomas uses for his one-handed drumming, Barnes would have chosen the prosthetic drumstick incorporating EMG technology, which is more expensive and would potentially take longer to develop. Therefore, cost is not necessarily a deciding factor for musicians with LDA in the pursuit of aesthetic control and expression. Furthermore, even with reference points, musicians with LDA will have their own preferences for approaching a musical instrument. However, if points of reference could be accessed and presented to a musician with LDA, they would understand the options available to learn or choose from.

Although expensive 'adapted prosthetic devices' may be time-consuming to produce, even cheaper, DIY devices may require a considerable amount of trial-and-error before creating a viable solution. Memmel describes the 'eight years' (Memmel 2016) of experimentation he had before finding the solution he still uses today:

I had never seen someone play guitar with one hand before... I noticed that the sound I could produce with my guitar with my arm alone was just not what I heard

on the radio. It wasn't what I wanted to be like. So, my hope was what if I could go around my house and construct [a device] with the tools I have at my immediate disposal; a cast that would help me play the guitar. So, I noticed when I first was playing guitar, that I do have this space on the end of my arm that's the perfect size of a guitar pick [plectrum] ...It's not strong like a muscle or like fingers, it's just a space... I went around my house looking for... clear [scotch] tape... duct tape, paper clips, glue, strings, socks; everything... and just try and make different devices (Memmel personal interview 2020, see Memmel 2016 and Thomforde 2016a).

Memmel was aware he had to go through the trial-and-error process, which took the form of creating different 'devices' for the space in his partially-absent arm. The immediate question for finding a solution will often be: what is at one's disposal? (see Dokumaci 2023, p.9 and Buck 2023, n.pag.). For example, musicians with LDA adapting to their musical instrument and everyday environment or devising a solution from cheaper materials would need to ponder this question. Memmel has found a workable 'adapted prosthetic device' for using a plectrum on the guitar. However, due to the nature of Memmel's LDA—a space in the crook of his elbow fit for a plectrum—his device is highly unlikely to translate to another guitarist with LDA.

Williams has a similar form of LDA to Memmel. However, he does not have a space in his elbow for a plectrum meaning he had to build a more sophisticated device for his needs. It is noteworthy that Williams chooses a virtuosic style of electric guitar playing including soloing in the hard rock/blues genre, rather than folk rock for Memmel, which emphasises chording on an acoustic guitar. Williams describes the plethora of materials he went through before he discovered the design he settled on:

I was six [years old] ...what I did [with my Grandad] was take apart one of my prosthetic arms. I used the shoulder harness... as a strong [base] and the guy that made my prosthetic arms had built a pick [plectrum] for a bass guitar player here in town that was... like a leather cuff... He didn't use a publicly available pick [plectrum]; he made his own out of a piece of plastic. And then he riveted that [plastic] onto the leather cuff and... it just did not work for me at all. It [the device]

was just too loose; I couldn't get any accuracy with it. So, that's when I got the idea to tear apart one of the harnesses from one of my arms and used that to attach to my arm. And I put the little metal ring round the end of my arm and put the nylon webbing strap around that side of my arm... It went through a bunch of iterations... I tried stapling it on at one point... I used paper clips... around the webbing (Williams personal interview 2019).8

Williams had different workarounds due to not having a suitable space for a plectrum in the end of his arm. He used a concept suggested to him, which did not work. He then reappropriated these ideas, and refined them for himself. This reinforces the notion of the individualised nature of LDA.

Although Dennehy was able to adapt to three different stringed instruments, the conventional adaptation of the guitar plectrum and cello bow also went through numerous iterations:

The bow for the cello; this was a great idea by Mrs. Petry. It's a little difficult to be able to hold a bow from the top looking-down. So, her idea was to take the frog [bottom attachment to the horsehair] of the bow; ... put it upside down on the top of the bow in the same adjacent spot... wrapped that up in tape and made it soft and cushiony. And I could hold that part of the frog with my big toe and my next toe...

That was really helpful because then I could hold it [the frog] and then apply pressure on the cello... For bass and guitar, there are definitely picks [plectrums] that work better for me than others. When I first started playing, I had a big issue with dropping picks while I'm playing... I really had to find the perfect pick... I tried those finger picks that attach to your toe... those didn't really work for me either... I did try the really flimsy light picks too... It didn't even feel like I could get much volume...

Now I've found a perfect... pick. It's a medium pick; but also at the top of it... a little bit of Velcro where I hold it... More often, I don't play with a pick at all and I even

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⁸ Upon review, Williams changed 'apart one of the artifices' to 'apart one of the harnesses' (see Ibid.).

strum with my toe and then a little bit with my nail too (Dennehy personal interview 2021).

It is intriguing to discover that through universal guitar playing devices (plectrums), which come in different shapes and sizes, Dennehy had to make adaptations for his own needs. It became a lengthier process, again showcasing the individualised nature of LDA musicality. For the guitar and bass guitar, this even led to bypassing a device by using his toes, even after finding a plectrum. For the cello, Petry, with Dennehy, was able to adapt a universal cello playing device (the bow) through alteration and utilising cheaper, household materials. These processes highlight how approaching the guitar, bass, and cello already have a myriad of responses, which LDA musicality further complicates.

Another consideration for LDA musicality is the need to keep the device and/or the instrument stable. Vanderhamm (2020) explains that Meléndez needed stability to accommodate his playing:

Placing the guitar on the ground is simple, and the lower bout [the curved parts of the guitar] easily supports his [Meléndez's] right heel (although Meléndez has had to seek out sturdier instruments and have some repaired that did not structurally support the added weight) (p.289).

Other musicians who play with their feet such as Mark Goffeney and Alvin Law have had to support various instruments with the use of stands and chairs (Caters TV 2016, Harris and Gonzales 2015, Quinn 2003, Schlatter 2017, and Law 2015). For the cello, guitar, and bass guitar, Dennehy highlights the materials he used to keep the instruments steady on the floor:

Those custom-made stands [for the cello]. I have the wood knobs and they hold the instrument up and tilt it... to sit on a stool and play... with our feet... My guitar... I put a mat under it. And I have a custom-made Styrofoam thing that attaches to the top of the guitar, so the tuners don't get out of tune, [and] so it can sit up just a little bit. When I was playing bass, I put... a wooden block... matted with tape... so it was soft.

And I put it under the neck of the bass, because a bass is flat; a guitar is rounded... so, the bass would sit... up, so it wouldn't get out of tune (Dennehy personal interview 2021).

Despite his various instruments being relatively similar, Dennehy has had to fashion different devices out of various materials to keep them both stable and in tune. Overall, 'adapted prosthetic devices' for LDA musicality are wide-ranging, with devices being built and designed for individualistic purposes.

4.4 The spectrum of instrument redesign from slight to wholesale changes

I want now to consider, the redesign of popular music instrumentation. Instrument redesigns range from slight instrumental changes such as using open guitar tunings and repositioning the drums, to significant changes including the creation of an entirely new instrument such as the one-handed saxophone. The section will proceed from the slight changes to the significant changes. First, many armless musicians have used open tunings and the use of barre chords (generally by fretting the big toe over the strings in a single fret). This will be followed by the notion of standardisation such as other armless musicians using standard tuning. Even the slight change of the repositioning of the drum cymbals to one side can still lead to ingrained pre-LDA habits being hard to break, such as Thomas being unable to become accustomed to playing the floor tom on the left. In addition, the importance of comfort and avoiding strain through body positioning and balance needs to be considered. From this, the section will shift to expensive changes which are typically carried out by musicians with adventitious LDA as they are aware of their previous musicianship pre-LDA. The two key examples presented here are Jason Barnes and Neill Duncan. Both Barnes and Duncan sought manufacturers for their expensive routes and were willing to compromise to do this, despite having cheaper and more adaptable options available to them. Furthermore, both musicians with LDA are advocates: Barnes for prosthetics and Duncan for the mass-production of a one-handed saxophone. To follow, the creation of new instruments for LDA musicality for mass-production is characterised by a struggle between creating a reduplicate of a commercially-available popular instrument and

an individualised solution. Then, the viability of popular manufacturers getting involved in the building process will be addressed. Potentially, accessible instruments may be a route; however, as already argued, it is difficult to translate these instruments to enable the aesthetic control and expression required for LDA musicality. To follow, the geographical distance and lack of localised provisions can be an issue, which can only be combated with the sharing of salient information. To finish, the potential of 3D-printing as a manufacturing option for instruments and devices will be considered for its currency and applicability. However, the trial-and-error associated with creating a fully-fledged, redesigned musical instrument prototype will be examined.

Depending on the genre, the perception of skill depends on how a musician with LDA interacts with their instrument as well as the capabilities of the instrument itself. Even if a genre is not concerned with skill, such as the 'anti-aesthetic' of punk (McKay 2016, p.226p.245), musicians with LDA have expectations for their aesthetic control and expression based on other players in their genre of music, and how long the musician with LDA has been playing their instrument (see Vanderhamm 2020, p.290). For instance, to sonically pass on their instrument, musicians with LDA need to have a level of musicianship that will create this aesthetic illusion. One method available to all musicians is utilising scordatura on the guitar to their own needs and proclivities. Numerous able-bodied musicians have used distinct tunings to utilise various techniques and genre conventions especially on the guitar (Ibid., p.289). For musicians with LDA, the versatility of the guitar (and potentially other stringed instruments) and its individual tuning positions is a universal tool available for sonic passing and, in some contexts, can be favourable for LDA musicality and other disabled musicality (Ibid., p.290). Armless guitarist Tony Meléndez uses open G tuning (Lubet 2019, p.315 and Guevara 2000), which is 'a tuning that produces a recognizable chord without fretting any strings' (Vanderhamm 2020, p.289). This example highlights how easily transferable these methods for playing the guitar are, and how musicians with LDA can be influenced to pick up the instrument because they can envisage how their musicianship can be translated.

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⁹ A notable example of a disabled musician using scordatura to facilitate her guitar playing is polio survivor, Joni Mitchell (McKay 2013, p.24 and p.26-27).

Vanderhamm (2020) presents the techniques that Meléndez utilised in order to play the guitar:

A C major chord in standard tuning requires fretting a string in each of the first three frets, the same chord... can be achieved in open G tuning by fretting all the strings within the fifth fret. Meléndez can thus utilize his left big toe to compress several strings at once within a single fret, and he often plays in the keys of D or G... using the open top string as a drone on the first or fifth scale degrees of the key (Ibid.).

The technique of pressing down on numerous strings simultaneously in a single fret is known as a barre chord. Armless multi-instrumentalist George Dennehy describes his use of barre chords and how feet are advantageous over hands for this particular technique:

Certain keys are easier for me that might be harder for other people like the key of E. I love the key of E because I can play the C Sharp Minor; ... B; ... A. And with my big toe, it's very easy for me to hit those three strings by themselves—a barre chord is super easy for me (Dennehy personal interview 2021).

Barre chords 'can be intimidating for beginning guitarists' (Thomforde 2018a). However, for Dennehy and Meléndez, their big toes were advantageous as three strings could be depressed simultaneously with consummate ease. The use of a big toe over a finger being beneficial for barre chords is logical because the surface area of a big toe is greater than that of the front of a finger. Although open tunings and the easy application of barre chords may be perceived as reducing the difficulty of playing the guitar for musicians with LDA, these universal guitar alterations facilitate originality (see Buck 2023, n.pag.). For guitarists with LDA, open tunings may be used out of necessity (a musical 'activist affordance', see Dokumaci 2023, p.7). Based on the perceived limitations of the foot as a music maker, it is understandable that an armless guitarist adapts in a manner, which is applicable for conventional guitarists who may also choose to use open tunings.

Meléndez recognises the importance of open tuning to his ability to play guitar chords, on an acoustic guitar: 'The tuning is the secret—that's how I'm actually able to form chords on the guitar. Two toes to make a minor, one toe to make a major, and sometimes a single toe to give a major seventh' (quoted in KXLY 2009 cited in Vanderhamm 2020, p.298, see Carah 2010). Despite this:

Meléndez himself sometimes uses other tunings, and other [armless] guitarists like Mark Goffeney and George Dennehy both play with their feet in standard tuning. Furthermore, Goffeney and Dennehy play in more blues—and rock—infused styles, providing proof that playing the guitar with one's feet does not necessitate a singular technique or stylistic approach. Meléndez's tuning accommodates his aesthetics as well as his body (Vanderhamm 2020, p.289-290).

The reason Dennehy may use standard tuning over open tuning is probably due to his musical training as a child. Along with his teacher Jennifer Petry, he developed the dexterity in his feet through individual toe movement, which facilitates the fretting of standard tuning. The utilisation of standard tuning is befitting of Dennehy's philosophy towards the guitar being as 'standard as possible' (Dennehy personal interview 2021, see Dokumaci 2023, p.5). Something as simple as a change in tuning can have a significant impact on a musician with LDA's music-making, which needs to be practised and tailored by them, and those assisting them.

Unlike the fine motor function of playing the guitar and other string instruments, the drum kit requires the gross motor skills of larger joints such as elbows, wrists, shoulders, and ankles. These movements still require careful consideration. The drum kit can be rearranged to suit the physicality of a drummer. A drummer who has utilised this repositioning to advantage his LDA (bypassing a partially-absent right arm above-the-elbow) is Jack Thomas. Thomas acknowledges that the ergonomic shift of placing all the cymbals to the left-hand side of the drum kit (to favour his unaffected left arm), was necessary for 'comfort and speed' and to feel satisfied with his LDA drumming. Although Thomas managed to adapt a conventional drum kit over time, he has been unable to move the floor tom over from the right-hand side (Drumeo 2020). Thomas explains:

Some habits are hard to break. I had about four years of drumming experience before my accident. That's four years of doing fills from left to right. It's comfortable for me, it doesn't strain me, feels great, and honestly, it gets out of the way of my cymbals (quoted in Ibid.).

This experience highlights how making changes to an instrument can be onerous. For a musician with adventitious LDA, they have had previous training and experience using conventional methods and thus, need to rewire their muscle memory. From one standpoint, a musician with congenital LDA adapting to a conventional, or using a redesigned, instrument learns to play virtually the same way from the beginning having been through the majority of the trial-and-error process. In contrast, musicians with adventitious LDA may have an advantage in the sense that they know what they achieved pre-LDA and therefore, know how they want to sound. Conversely, musicians with congenital LDA have no point of reference when they want to learn to play an instrument.

Many musicians with LDA work on developing the muscles they use for playing, or compensate by utilising muscles which are not typically used. In his Drumeo tutorial, Thomas consistently speaks of avoiding strain and being comfortable when playing the drums:

If you have two arms, you're balanced out... Obviously, I'm very left-side heavy. One of the most important things... was how can I be sitting in the best position to make sure I am stable and doing things without... hurting myself and doing things as fluently as possible? And it honestly all came down to core strengthening; ...the height of my drums; making sure my throne [drum stool] is nice and high... shoulders back straight; all things you've all heard from your drum teachers (quoted in Ibid.).

Body position and comfort play a pivotal role for musicians with LDA to achieve their music-making aims. With all these considerations, it could be said that Jack Thomas, and the drum teachers he refers to, are musical occupational therapists for their instruments. This is applicable for the majority of musicians with these particular needs.

In terms of expensive wholesale instrument changes, a difference between instrument overhauls or expensive equipment and DIY adaptive music is that typically redesigns are made by 'accomplished professionals who acquired their disabilities after establishing careers' (Lubet 2019, p.317). This is logical because musicians with congenital LDA are unlikely to spend extortionate amounts of money without any reference points or a baseline for their own musicianship. A musician with LDA who pursued a wholesale redesigned instrument is Neill Duncan and his one-handed saxophone. Of course, Duncan was an experienced saxophonist before he lost his left arm, above the elbow. This partial (and in a musical context, full) absence of his left arm would likely be thought of as career-ending. Therefore, the question for Duncan was: what was required to realise his pre-conditioned musicality on the saxophone? With the collaboration of Maarten Visser (manufacturer of the one-handed flute), a new one-handed saxophone was created (Flute Lab 2021, Duncan personal interview 2018a and 2018b). Duncan has been able to play the one-handed saxophone successfully for public performances (Duncan 2018b). However, Duncan's control did change, describing playing this saxophone as, 'counter-intuitive' (Rose 2016), and his new style as, 'fragile' (Duncan personal interview 2018a):

It's [the one-handed saxophone] made my playing a lot more fragile. The recordings I listen to... are the players who show their fragility. Ornette Coleman... Charlie Parker's [ballad playing] on *Lover Man* (1946) ...I've always loved that fragility in playing... I've always had this style that's strong, but now I don't. Now, all of a sudden, I've been forced to this fragility in my playing and I really like it. The horn is so limiting in some ways but in other ways, it's opened up possibilities for a new sound and a new style, and new intervals because my fingering is not the same (Ibid., see Rose 2016).

Arguably, Duncan has lost some control due to playing unexpected new intervals. However, by referencing saxophonists he enjoys from the genre of jazz (Coleman and Parker), Duncan is satisfied and accepts this difference. This suggests that musicians with adventitious LDA may never have the same musicianship post-LDA. Therefore, this group of musicians have to

accept a newly discovered type of musicianship, which still incorporates a desired level of aesthetic control and expression, and is befitting of their genre conventions and techniques.

It is intriguing that Duncan would choose to play a redesigned saxophone rather than play the standard saxophone with one hand. Several musicians have played the saxophone onehanded and played two saxophones simultaneously. A notable example is blind experimental jazz multi-instrumentalist, Rahsaan Roland Kirk, who would play two (or more) saxophones simultaneously (McKay 2013, p.14). Perhaps Duncan felt that to emulate the style he desired, he needed to play an entirely redesigned one-handed saxophone rather than play a standard saxophone with one hand. This has parallels with Jason Barnes deciding to pursue the potentially longer and more expensive process for his prosthetic drumstick. Barnes had to find a manufacturer and funding and even compromise by having a two-stick design in order to obtain the use of EMG technology he desired rather than adapting to a conventional drum kit like Thomas (Barnes personal interview 2019). Another connection between these two musicians with LDA is that both advocate for the technology they use through various public performances and speeches. For Barnes, this advocacy is for the betterment of prosthetics as a field, and for Duncan, the advocacy involves finding a suitable prototype for the one-handed saxophone, with a view to mass-production (Barnes personal interview 2019, Duncan personal interview 2018a and 2018b).

Such was the cost of Duncan's saxophone, he had to be financed from various sources before the lengthy process of building his adapted instrument began:

The community came together; my colleagues came together. There was (sic)... a number of benefit concerts. [The] Government department came together and thanked me. [They] all joined together to try to raise the number to build this instrument because it is an expensive process and it took roughly a year and a half to build this (Duncan 2018b).

A problem with this part of the trial-and-error process is that there are no guarantees that the musician will find the right prototype. After Jack Thomas' factory accident, he was inspired by Rick Allen's return to drumming. This led to funding being provided for the

electronic drum company, Roland to make Thomas a drum kit; akin to Allen's hybrid kit with fellow electronic drum company, Simmons (Stewart 2015, and 65 Drums 2017). However, over time, Thomas found that adapting to a traditional drum kit was favourable over using expensive drum equipment. Thomas was able to use his left foot for hi-hat control and the double bass pedals rather than a pedal-operated snare. Additionally, Thomas, through his personal experience and influential figures around him, was able to play the snare and around the drum kit with his one-handed techniques (Drumeo 2020).

In the pursuit of mass production for an adapted instrument for LDA, there is a dichotomy between the need to reduplicate instruments to make them commercially viable, versus the desire for musicians with LDA and manufacturers seeking to individualise the instrument to their needs. Subsequently, the costs of these redesigned instruments may mean musicians with LDA revert to conventional models of instrumentation, where micro (rather than macro) changes are made. From the perspective of music and disability organisations, cofounder of The One-Handed Musical Instrument Trust, Stephen Hetherington states that adapted instruments are not generally suitable for mass-production due to the individual wants and needs of disabled musicians:

You can produce a trumpet in China and produce 100,000 of them. But if you're going to have an instrument that is for a disabled person, only a relatively small number can be produced for a certain type of disability. In addition, with adapted instruments, you're constantly changing and manipulating the instrument to make it possible for that particular player (Hetherington personal interview 2018).¹⁰

The individualised nature of LDA is problematic as producing bespoke instruments in smaller quantities is not financially viable for companies. Hetherington comments on the difficulties of getting popular manufacturers interested in making adapted equipment for LDA musicality:

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¹⁰ Upon review, this quotation was edited as per Hetherington's request (see Ibid.).

Popular manufacturers have really good equipment that OHMI want to get our hands on—the Yamaha Wind Controllers, for example. Some of the equipment is quite sophisticated, and then suddenly we hear that they're not making them anymore (Ibid.).¹¹

Hetherington elaborates on the inner-workings of these organisations:

The design teams of these organisations are hard to find and their policies and funding shift quite dramatically and quickly. It is difficult to get any interest from the main companies because basically, there's no sales. The instruments would only be provided as either a marketing exercise or an act of altruistic generosity (Ibid.).¹²

The (now) former CEO of Drake Music (a music and disability organisation which utilises accessible music technology), Carien Meijer, explains the experiences she has had:

We get given quite a bit [of equipment], actually. And there's a real interest on the part of some companies... for us [to] look at their products and suggest how it could be made more accessible, for example. So, again, that's a whole area where... we began... to develop and build partnerships and potential for future collaborative incentives... It could be expanded. But yeah, ... any small organisation will say this, 'we're very, very under-resourced ... and we don't always have sufficient expertise in-house'. So ... there is huge scope to take it beyond ... where it is and what it is ... But I think it should [be] ... much more widely available (Meijer personal interview 2022).

The reason that Drake Music may have had more success than OHMI is because their model is geared towards accessible music-making meaning that there are fewer barriers to entry for the popular musical instrument manufacturers to become involved. However, OHMI is more interested in the nuances of one-handed musical instrument playing and other

¹¹ Upon review, this quotation was edited as per Hetherington's request (see Ibid.).

¹² Upon review, this quotation was edited as per Hetherington's request (see Ibid.).

aspects of disabled musicality, which involves aesthetic control and expression. If there were a method for translating accessible musicality with the aesthetic control and expression of LDA musicality, perhaps manufacturing processes could be improved for musicians with LDA to play accessible musical instruments.

With the difficulty and lack of financial viability for mainstream manufacturers to create bespoke instruments, it is logical that the altruism of the community is needed to offset these costs. The community is less likely to raise the same funds if a person with congenital LDA has the intention of playing a bespoke instrument or with an expensive device. Whereas, musicians with adventitious LDA have a baseline for their previous musicianship. There are no examples (to the best of my knowledge) of musicians with congenital LDA making wholesale instrumental changes. Instead, these musicians prefer to adapt to an instrument or use a cheaper, DIY prosthetic device. This is because musicians with congenital LDA have no indication of their music-making proclivities when they first consider playing an instrument. For example, Tony Memmel had never seen a one-handed guitarist before he started to play, and the guitar teacher he approached felt unable to teach him (Memmel personal interview 2020). Whereas, musicians with adventitious LDA will be able to compare their pre-LDA musicality with their ambitions for their post-LDA musicality.

In the pursuit of mass production, a suitable prototype is required. Therefore, the collaboration of the manufacturer and the musician with LDA should be encouraged where possible to ensure the prototype is appropriate as the process advances. Duncan described the long process he went through to get to the second stage of the prototype process, where Maarten and Duncan would collaborate in person:

He [Maarten] sent me ideas and said... 'I can do an open-hole system or a closed-hole system'... I think to play the closed-hole system would be difficult but in the long run means you'll be able to play everything'. So, I thought: 'Oh, of course, that's the one to go for'... He would send me photographs of the keys and go: 'Does this key look like it would work for you?'... On Monday [September 2018], I'm going over with the horn and now I've got some ideas because I've had it for four years and... now I can say to Maarten: 'This doesn't work. This would be better over here. This

would be better if it had less movement and this would be better if it was a rod and not a cable'... Maarten's very excited... because now, we can collaborate... Through that collaboration, because of the experience I've had with the horn and because this was a prototype, we can now get it pushed to that next level and hopefully push it towards the idea of getting them mass-produced for people to play saxophone (Duncan personal interview 2018a, see Duncan 2018c).

The lack of control mentioned earlier where Duncan would play unintended intervals (Duncan personal interview 2018a and 2018b, and Rose 2016), may be attributed to the original prototype of the one-handed saxophone being less than ideal. I asked Duncan about the prospect of mass-producing the one-handed saxophone:

Well, it looks like they [manufacturers] are doing it with the recorder with the 3D-printing, which is a start... I would imagine as technology moves ahead, they could probably do that with the saxophone as well. But what we need is a good prototype... which is what me and Maarten [will] look at... pushing it towards; ...that perfect prototype. And then I'll take that home and maybe a year after... we might be getting closer and that's when we can go, 'Okay, can this be done on a 3D printer?' (Duncan personal interview 2018a).

An issue with this particular collaboration (and numerous others) is the geographical distance of Duncan (Australasia) and Visser (The Netherlands). Duncan's appearance at the 2018 OHMI conference in Birmingham was funded (Ibid.), which was the only way he could collaborate with Visser in person. In-person meetings are the best method for comprehensive collaboration and key discussions between the musician and manufacturer. This is because it is difficult to explain design and manufacturing intricacies over the Internet, whereas, when in person, the instrument can be played by the musician and altered by the manufacturer immediately. These changes are deliberate as they typically take long periods of time and vast amounts of money. Additionally, with the correct prototype, 3D-printing may eradicate the geographical issue, as plans and blueprints could be sent online to be printed and modified by local and specialist manufacturers.

In contrast to the long-distance collaboration of Duncan and Visser, Thomforde wanted to use local expertise in order to adapt a recorder to utilise her seven digits. This process required countless conversations with local practitioners in the North-East of the USA before she was able to locate an expert in the UK:

I went to this recorder workshop ... and showed the guys there what I was doing with the brace I had and said: 'What could I do to get a customised instrument? How could I play the full range of the recorder?' ... Eric Haas [US recorder specialist] ... figured out that if I had a key on holes 4 and 5, I could use my left pinky to do both of those. So, I could ... play the whole range of the instrument. So, they couldn't do the key work there and so I started asking around. Early music shops and instrument makers and instrument repair people with outside [expertise]: 'Is there a way I could get two keys put onto a recorder?' And they all said: 'That was really expensive and really difficult' ... And I contacted recorder companies ... and everyone told me: 'No'. And then eventually, someone told me about Peter Worrell in the UK ... I reached out to him and he said he could do it. And judging by what I had seen on his website ... I thought he was just the perfect person to do it and he did (Thomforde personal interview 2022, see Thomforde 2018b and 2020).

This example stresses the importance of disseminating information, as it took a concerted effort by Thomforde to have discussions with all manner of experts and practitioners, who were unable to help her solve her problem directly. It was not until the suggestion of Peter Worrell who has a specialist knowledge of adapting woodwind instruments (Worrell 2020) that Thomforde was able to find a solution. However, this adaptation needs to be communicated to workshops and makers in other countries to avoid the rigmarole Thomforde endured.

Thomforde explains that her recorder is not an exception, as obtaining the perfect instrument is difficult to achieve. However, if the situation is to change, information and resources need to be shared more broadly:

The more people that do this, the more people who hear about it, the more people who will think it's possible [building or modifying an adapted instrument] ...Now if I went to some of those instrument makers that I reached out to years ago and who decided it was just too difficult and showed them: 'Hey look, this is my instrument. This is what I can play' ... I have to imagine that people would be ... supportive and impressed and think ... it is possible. I think oftentimes, if you haven't seen something done before, you may jump to the mindset that it's too hard (Thomforde personal interview 2022).

The lack of proof that Thomforde's adapted recorder was viable may be why makers and practitioners in her local community were unable to help. This mentality has parallels with teachers thinking they cannot teach musicians with LDA. This again suggests that collaboration is needed across different fields in order for more people to understand what is possible. Thomforde hypothesises that 3D-printing is better for the construction of devices rather than for instruments (Thomforde personal interview 2022). This is evident from a list of 3D-printed instruments, which are mostly printed in parts rather than fully (Kantaros and Diegel 2018, p.1516-1521). The matter of 3D-printing suggests that producing instruments in greater numbers than one, may be a longer process. This is because the correct prototype needs to be manufactured, as was experienced by Visser and Duncan (Duncan personal interview 2018a). 3D-printing seems to be accessible for the building of devices because they are smaller than full-size instruments. The devices may be single purpose, whereas, instruments need to be playable in various ways.

Despite 3D-printing appearing to have the potential for being an integral part of the manufacturing process of devices and instruments for LDA musicality, I do not believe this is the case. Even though Duncan and Visser went through a lengthy prototyping process, after four years of collaboration, there was still more to do (Duncan personal interview 2018a). Duncan acknowledges the 3D-printed one-handed recorder; however, the recorder is a far smaller and less complicated instrument than the saxophone in terms of having fewer components and the materials used. Therefore, it seems that 3D-printing may be suitable for adapted prosthetic devices as the requirements for a device are far less than a comprehensive redesign of an instrument for LDA. Thomforde has had limited success

building devices on a local 3D-printer more as an exercise (Thomforde personal interview 2022). However, based on the evidence of various musicians with LDA, they have more success building their own devices for connecting to an instrument or keeping the instrument stable with DIY materials by themselves or through 'non-experts'. 3D-printing is likely to be a lengthier and more expensive prototyping process than a musician with LDA using materials at their disposal matched with resourcefulness and ingenuity.

4.5 Summary: LDA musicality's position within adaptive musicality

Regarding aesthetic control and expression, musicians with LDA will use different methods, devices, or instrument modifications to connect their instrument to their LDA, or bypass their LDA through the employment of alternative limbs. If the musician is able to connect to the instrument, another consideration is how to keep the instrument stable and positioned correctly. These two considerations are mutually reinforcing because having a stable instrument without connection and vice versa is useless. Although the musicians with LDA studied have often been able to get the degrees of aesthetic control and expression they demand, methods, devices, and instruments are likely to need changing over time and by varying degrees. Therefore, LDA musicality is defined by trial-and-error in order for the musician with LDA to find their desired method, device, or instrument redesign. Medical intervention and the therapeutic and rehabilitative benefits of playing a musical instrument can play a pivotal role in the physicality of LDA musicality. The fields of occupational and physical therapy have been shown to advantage the physical development of LDA. Extending beyond this, playing a musical instrument can help relieve phantom pain and create a sense of body completeness for musicians with adventitious LDA.

A further consideration for LDA musicality is the fact that there is a wide variety of methods, devices, and instrument redesigns ranging from slight, cheaper changes to wholesale, expensive modifications. A relatively small change to an instrument can facilitate LDA musicality. In fact, universal techniques can be advantageous for musicians with LDA. On some occasions, these techniques can be borne of necessity where comfort and control may be more easily managed. Due to the difficulties described, some musicians with LDA have

resorted to a standardised approach, or the most logical approximation to conventional musicality. A technique which supports this standardised approach is the ability for musicians with LDA to 'sonically pass'. This can be defined as a musician with LDA utilising certain tools or methods to produce a sound, which closely resembles other players in their genre. For a professional musician with LDA, this form of passing allows their music-making to be accepted by audiences as the 'sounds' fit within their expectations. In fact, a musician with LDA's aesthetic control and expression can be such a success that able-bodied musicians will replicate these methods for their own playing. When making devices and adapting to instruments, some musicians with LDA have taken ideas and concepts from other aspects of music, or even everyday life. A musician with LDA's musicality is defined by the creativity and resourcefulness employed when approaching their instrument.

When comparing the cost of creating and modifying devices and instruments, the evidence suggests that slight instrument changes are typically low-cost or relatively cheap; whereas, extensive instrument redesigns are expensive. To achieve the production of these devices and instruments in greater numbers, the option may be collaboration. However, a problem is that the trial-and-error process and the individualised nature of LDA still remain. Usually when instruments are redesigned, it is to enable musicians with adventitious LDA to regain their musicality, requiring considerable funds to do so. A musician seeking this avenue usually needs funding from altruistic groups of people. The high costs of redesigning an instrument would unlikely be an option for prospective musicians with congenital LDA because these musicians do not have any experience of playing a musical instrument. This could potentially lead to having a new, expensive instrument which is unusable. Whereas, musicians with adventitious LDA have plenty of experience and have a direct comparison to how they previously played their instrument.

The prospect of 3D-printing may have the potential for mass-production, if a better prototype could be created. However, the ability to mass-produce musical instruments to facilitate LDA musicality has proven difficult. This is because the comprehensive redesign of a musical instrument already needs a proven prototype before anything can even been considered to be 3D-printed. Furthermore, adapted prosthetic devices have typically been manufactured through DIY processes rather than through the 3D-printing route. From the

perspective of popular musical instrument manufacturers, there is little interest because the individualised nature of LDA equates to limited sales of these adapted instruments.

Fundamentally, the methods, devices, and instruments explored should be perceived as an extension of all music-making, rather than only being applicable for musicians with LDA. These resources are not a novelty. Instead, these designs and methods should be regarded as applicable for any musician and genre, with the potential to be used and emulated by prominent musicians or even transcend the genre. Although this philosophy of LDA musicality being applicable to all musicality may seem to run counter to the individualised nature of LDA, the knowledge of these resources and potential access to them could act as reference points. This is not to say that musicians with LDA will definitely use a reference point simply because it is available to them. My argument is that if more reference points for LDA musicality were more easily accessible and shared more widely, musicians with LDA, device and instrument designers and makers, and teachers would understand the options at their disposal, which they could choose to pursue or disregard (not entirely, only personally).

There is seemingly a distinct lack of information for musicians with LDA to find successful solutions for the methods, devices, and instruments they need. However, it is evident that musicians with LDA are willing to share their everyday and musical methods, devices, or instruments with anyone who needs assistance. Additionally, practitioners from other fields and non-experts want to help musicians with LDA. In some instances, non-experts have been able to create better devices than experts. This could relate to the non-expert having a personal link to the musician with LDA and being more in tune with their needs. This investigation of the diversity of LDA music-making in terms of the laborious, yet necessary, trial-and-error process and the ingenious solutions and determination required to play a musical instrument to the musician with LDA's individualised requirements, has been illuminating.

Chapter 5 – The Value of Organisational Support for Musicians with LDA

Access to the right musical instruments and technology can be powerful and transformative.

Drake Music (2022a)

There's no communication and sharing between all within music and disability.

There's no central place for these people to work from. There's a lot of material around centralising music and disability information that OHMI would love to get to grips with.¹³

Stephen Hetherington of The One-Handed Musical Instrument
Trust (personal interview 2018)

In this chapter, the first half of the third research question is going to be investigated: 'What level of organisational and institutional support is there available for musicians with LDA and what are the potential implications of this support or lack thereof?' To unpack this research question, I will identify and examine the broader and representative insights of key relevant music and disability organisations in the UK, USA, and internationally. The rationale being that these organisations offer different levels of support including: aiding professional and/or amateur musicians; having numerous funding structures; differing job roles; various music-making projects and collaborations benefitting musicians, and device and instrument makers and designers; and using branching avenues such as promotion, teaching, and technology. I have selected four music and disability organisations as case studies. Rather than investigating many organisations assisting musicians with LDA, which may simply not be comprehensive enough, these four organisations cover a plethora of musical needs for various musicians with LDA in locations internationally. Furthermore, several of these provisions have supported musicians with LDA directly. These four organisations are: The One-Handed Musical Instrument Trust (hereinafter abbreviated to OHMI); Drake Music;

¹³ Upon review, this quotation was edited as per Hetherington's request (see Hetherington personal interview 2018).

May We Help in collaboration with the Adaptive Music Project, specifically the Cincinnati Adaptive Music Camp (hereinafter abbreviated to CAMC); and Can-Do Musos.

Here I will explain why I have decided to select these four organisations. The first two are notable UK-based music and disability organisations. First, OHMI is the most relevant music and disability organisation particular to the special interest area of LDA precisely because OHMI was founded to address an aspect of LDA musicality: specifically one-handedness (the impetus being co-founder, Stephen Hetherington's daughter, Amy, who has hemiplegia which affects the use of her left hand for trumpet playing, hence the one-handedness of OHMI) (BBC News 2013, and OHMI 2022d). OHMI has a strong, wide-ranging infrastructure, which covers various needs of musicians with LDA such as device and instrument making and designing (OHMI 2016b), adapted instrument hire for cheaper equipment (OHMI 2022e), teaching (OHMI 2022h), and research across music and disability as a whole (OHMI 2022g). The second UK organisation to be examined is Drake Music as it is positioned at the intersection of music, disability, and technology (Drake Music 2017b). Drake Music is a wellconnected organisation with personnel and projects assisting disabled musicians in professional settings (Drake Music 2022h); providing adaptive instruments and assistive technology for disabled musicians in classrooms (Drake Music 2022b); overseeing an open community of assistive music technology makers and designers called DMLab (Drake Music 2022c); and housing a collection of adaptive equipment and resources to be accessed by disabled musicians and relevant, interested practitioners who assist them called the Accessible Musical Instrument Collection (Drake Music 2022a).

The remaining case studies are not UK-based. One is US-based and the other operates globally. Both are music and disability organisations that have significant links to assisting musicians with LDA. One case study involves the collaboration of May We Help (an organisation which constructs equipment for disabled people across everyday and recreational activities) and CAMC. Although the in-person collaboration being only a week long may not be ideal, the project provides a good model for investigation. The specificities of this collaboration present the potential of linking the volunteer makers and designers for everyday equipment, which can translate to the construction of assistive musical equipment. May We Help provides the infrastructure of personnel, resources, and

designing, and having their headquarters in Cincinnati allows CAMC to draw upon May We Help's resources and engineers free of charge (May We Help 2020c and 2020h). Cincinnati provides a space for in-person collaboration and communication for the designers of May We Help, the teachers of CAMC, and the parents and children May We Help assist (May We Help 2020c). The final organisation to be researched is Can-Do Musos. The organisation operates differently than the other case studies by acting as an intermediary for assisting (mostly) professional disabled musicians around the world (several of whom have LDA) by paying the costs involved in facilitating in-person networking, performing, and recording of music between numerous disabled musicians. In addition, Can-Do Musos uses its funding to help disabled musicians get the assistive equipment they need (see Segal personal interview 2020). As another form of promotion, Can-Do Musos' website has personal biographies of their worldwide members and information related to some of their most significant promotional projects (Ibid. and Can-Do Musos 2017c).

In order to understand the operations and principles of these four organisations, senior members of these respective organisations have been interviewed by me as part of this research. These interviewees are: chair and co-founder of OHMI, Stephen Hetherington; former CEO of Drake Music, Carien Meijer; co-founder of CAMC, Jennifer Petry; and cofounder of Can-Do Musos, David Segal. To further inform this critical original data, the websites of each organisation will be examined to provide context for their organisations' practices and philosophies. It is worth noting that the language used on these websites is a method for self-advertising to key (potential) investors and supporters. To understand the practices and philosophies of these organisations, certain aspects which constitute each organisation will be studied as follows: the origins of the organisation or, in the case of May We Help and CAMC, their collaboration; the remit and mission statement; the various types of personnel employed or closely associated with these organisations; how these organisations are funded and how this funding is distributed for certain projects and collaborations; and the most significant collaborations and projects offered by these organisations. The rationale for this structure is to understand the similarities and differences in the ethos, operations, infrastructure, and practices of these organisations. It is important to state that rather than examining all aspects of an organisation's funding, this chapter will focus on substantial, high-level funding. Based on the information gathered

from these case studies, a discussion on the range of organisational support available for musicians with LDA will be presented.

To understand the potential collaboration between music and disability organisations and musicians with LDA, I also surveyed a small number of UK-based music education hubs to gain a general understanding of the connections between these groups. The reasoning for this is that it is important to understand the broader landscape of LDA musicality expanding beyond musicians with LDA, and organisations assisting them in order to understand the position of music education hubs. For the convenience of the respondents, I contacted the music education hubs by email requesting to survey the person at their hub who is best suited to my level of inquiry. I allowed the survey respondents to provide their answers in the body of the e-mail thread (see Schonlau et al. 2002, p.1). The reasons I used e-mail surveys for music education hubs over the primarily used interview method are that surveys are less time-consuming for both parties and require a shorter and more straightforward line of questioning, and follow-up on towards the end of the process (see Ibid., p.2, p.5, and p.7).

Throughout the thesis, semi-structured interviews provided the musicians and organisations the opportunity to speak extensively about their experiences regarding specific areas of LDA musicality. Whereas, the information from music education hubs that I wanted to obtain covers the broader landscape and peripheral areas of LDA musicality rather than specificities. This suggests that surveys were the most effective method to use. With this rationale, I asked three broad questions contacting over a dozen music education hubs in the UK in the hope of receiving replies from at least two or three of them. The reason for this being to gain an overview of their infrastructure, operations, and collaborations in relation to assisting disabled musicians (having provided a Participant Information Sheet for each respondent with details of the study being focused on LDA musicality, see Appendix 2). Based on the lack of responses to my initial email, I believe that there are several hubs which would be unable to provide salient information. However, two of the three people who responded clearly understood LDA musicality and their position within their respective hubs provided potentially suitable connections between music education hubs, organisations, and musicians with LDA.

5.1 Organisational support case studies

5.1.1 - OHMI

OHMI was formed in 2011 when co-founder, Stephen Hetherington, and his daughter Amy, who has hemiplegia, realised that the trumpet she played was not suitable for her needs (BBC News 2013, OHMI 2022d). Hetherington realised that this issue affected a wide range of disabled musicians, which he wanted to address (Ibid.). OHMI's mission statement is 'to remove the barriers to music-making so as to enable full and undifferentiated participation in musical life' (OHMI 2016a). Although the entire removal of music-making barriers may be unattainable, this use of language provides current (and potential) funders an insight into the ambition of OHMI. OHMI has a team of applicable practitioners available for specific projects and collaborations from their Birmingham headquarters, and around the UK. The organisation is overseen by core staff with extensive experience across adaptive musicmaking, along with the administration to monitor their fundraising activities (OHMI 2022i). Furthermore, OHMI has trustees including: the co-founders, Stephen Hetherington and Martin Dyke; as well as limb difference specialist consultant surgeon, Ruth Lester; Professor in Digital Media (including electronic music-making) at Queen Mary University, Andrew McPherson; Professor of Education at Birmingham City University, Martin Fautley; and the university graduate who recently founded the charity, Amputee Musicians UK, Emma Brown. Regarding the patrons and ambassadors of OHMI, they are professional musicians with an interest in music and disability advocacy such as saxophonist John Harle, deaf percussionist Evelyn Glennie, and pianist with LDA (born without his right hand) Nicholas McCarthy (Ibid.).

OHMI is endorsed and funded by dozens of advocacy bodies such as trusts and foundations. Two of the most significant funders are key UK funding bodies, Arts Council England and Youth Music (a subsidiary of Arts Council England) (OHMI 2022f). OHMI distributes the funding they obtain through four key elements:

- 1. The development of adaptive musical instruments, devices, and equipment through their international event, the OHMI Competition (OHMI 2016b).
- 2. Making adaptive instruments and apparatus available through their Instrument Hire Scheme (OHMI 2022e).
- 3. A teaching support programme known as Music-Makers (OHMI 2022h).
- The creation of a research group involving music education, instrument design and manufacture, and other aspects of music and disability known as The OHMI Research Partnership (the "ORP") (OHMI 2022g).

OHMI has numerous projects which provide the groundwork for their philosophy and remit. The most significant project OHMI is in charge of is the OHMI Competition (OHMI 2016b). It gives instrument and device makers and designers around the world the platform to present their finished project, work-in progress, or a blueprint of their designs. The OHMI Competition is divided into three categories: 'Playable, Enabling, and Concept' (OHMI 2017). 'Playable' instruments are categorised as fully finished original musical instruments (which can be played with only one hand), or an electronic version of an emulated instrument. 'Enabling' is reserved for apparatus which facilitate traditional instrument playing for one hand. Finally, the 'Concept' category refers to instrument and device designs presented through videos and drawings, which could become a 'playable' or 'enabling' instrument or device in practice (Ibid.). Once the category winners have been chosen, OHMI collaborates with the instrument and device makers and designers to tailor these designs to numerous physical differences and expand their usefulness (OHMI 2016b). Although providing the winning designers and makers a platform to showcase and promote their devices and instruments, the notion of a competition runs counter to inclusion and accessibility because many designs have to 'lose'.

When I asked Hetherington about the judging mindset for the competition, the consensus is that the focus should be on the capabilities of the instrument or device:

The judges each come with their own personal views and you can't regulate them.

You give them a rulebook and we do debate criteria. I don't think there's ever been a

dispute that led to an argument that we couldn't resolve regarding which instruments deserved to be the winners (Hetherington personal interview 2018). 14

Regarding the judges of the OHMI Competition, they are described as 'an independent panel of experts in the fields of performance and engineering, many of whom have "lived experience" of physical disability' (OHMI 2022b). Previous judges have included classical musicians with LDA such as violinist Adrian Ananatawan and pianist Nicholas McCarthy (Ibid.). It is positive that musicians with LDA are included in the judging process, however, many of these musicians (non-LDA and LDA) are from the field of classical music and/or virtuosic performers.

Typically, buying adapted instruments is outright expensive (see Lubet 2019, p.316-317). OHMI is aware of this fact, hence why they set up the Instrument Hire Scheme (OHMI 2022e). This project provides adapted instruments and enabling devices to be available for hire to disabled musicians for an annual fee. The scheme alleviates some of the financial issues associated with expensive adaptive music-making, by providing equipment, 'at a maximum of 15% of the retail value of the instrument for a one-year rental' (Ibid.). This project is a sensible solution for disabled musicians because if the musician decides to stop playing the instrument or using the device at the year's end, they have taken less of a financial risk. Furthermore, if the musician carries on playing after a year, the instrument or equipment can be re-hired or bought outright if they are confident enough on their instrument or through their enabling apparatus. Alternatively, the learning of an instrument can be translated to a second instrument, which they prefer or may be more suited to their needs.

Another important aspect of OHMI's practices is the teaching support programme, Music-Makers (OHMI 2022h). To complement the hiring of adapted instruments and enabling equipment (or any alternative options), OHMI has collaborated with organisations to improve teaching provisions across the music education sector including giving advice to device and instrument makers and designers, schools, teachers, music education hubs, and

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¹⁴ Upon review, this quotation was edited as per Hetherington's request (see Ibid.).

pupils on an individual or whole class level (Ibid.). Initial pilots took place in Birmingham in 2015, and Surrey and Hampshire in 2016, with a view to extend these schemes across the UK (OHMI 2022d). The integration of new adapted instruments and devices within mainstream circles may allow for their acceptance. Overall, the in-person collaboration and communication across the music education sector facilitates a more fulfilled mainstream music education with the inclusion of disabled children. The fourth key goal of OHMI's operations is The OHMI Research Partnership (the "ORP") (OHMI 2022g). This project was launched in 2019 as a collaboration between OHMI, Queen Mary University, and Birmingham City University. The rationale for this research partnership is to enhance communication between practitioners across, and on areas linked to, music and disability around the world, and to expand knowledge of the other areas of their operations (The OHMI Competition, Instrument Hire Scheme, and Music-Makers) (Ibid.).

In summary, OHMI has gained a worldwide reputation for improving disabled music-making provisions for a wide range of practitioners across music and disability. This reputation brought together practitioners from around the world at the 2018 OHMI conference (see Hetherington personal interview 2018 and OHMI 2022i). Although it is useful that OHMI has the information from its competition available on their website (OHMI 2016b), this knowledge needs to be shared more widely. This sharing would have the potential for musicians with LDA to find these instruments with greater ease; provide instrument and device makers and designers a reference point in order to make or modify these instruments themselves; and stockists could have these adapted instruments promoted far and wide. However, OHMI is a relatively small organisation (see Hetherington personal interview 2018). OHMI has important and long-term funding from key funders as well as several trusts and supporters (OHMI 2022f), which allows OHMI to remain ambitious. Although some of OHMI's activities have spread across the UK, many are localised to their Birmingham base such as collaborating with and using the spaces of Birmingham City University and the Royal Birmingham Conservatoire (the location of the OHMI Conference) (OHMI 2022d). Finally, the OHMI Research Partnership (the "ORP") has potential to expand knowledge of music and disability to improve provisions, resources, and expertise in the future (OHMI 2022g).

5.1.2 – Drake Music

Drake Music is one of the longest-running music and disability organisations, dating back to the mid-1980s. The (then) Drake Research Project was founded by Adèle Drake (Drake Music 2022f). Throughout their history, Drake Music has been geared towards accessible music technology to facilitate disabled people's music-making (Ibid.). Drake Music has three main aspects to their mission statement:

- 1. 'We are always learning, and always sharing what we learn.
- 2. Disabled musicians are at the heart of what we do.
- 3. Our work is underpinned by the Social Model of Disability' (Drake Music 2022j).

The organisation has a number of in-house practitioners available for various projects and commissions across the UK to assist disabled musicians, technologists, and teachers to have access to inclusive music-making (Drake Music 2017a). When developing ideas and concepts, Drake Music's practitioners are informed by the principles of open-sourcing such as sharing code for hackable technology or providing lesson plans for music-making (Drake Music 2022j). With advances in technology and their reduced costs, music, disability, and technology can be connected more easily. This means that makers and 'hackers' can build instruments and devices more efficiently and cost-effectively. In recognition of this shift, Drake Music established the DMLab in 2010, which combines 'accessibility with cutting-edge technology' (Drake Music 2022f, see Drake Music 2022c and 2022p, and Meijer personal interview 2022). Meijer discusses through an aspect of Drake Music's practices, DMLab, that sharing is key in order:

to really focus on bringing together disabled musicians, technologists, coders, hackers, instrument designers, makers, thinkers ... look at the idea of hackathons at work ... simply running our first hackathon ... and out of that grew a community that we call 'DMLab'' (Meijer personal interview 2022, see Drake Music 2022c).

The DMLab has parallels with the 3D-printing community because of the inherent opensource mentality, which means that sharing is widely encouraged (Samuels 2019, p.154, p.158-159, Bell et al. 2020, n.pag, and Frid 2019, p.2-3). For example, the websites 'Thingiverse' and 'Shapeways' are used to freely share designs to any 3D printer in the world, mainly for designers and users (Thierer and Marcus 2016, p.848). Furthermore, Drake Music practitioners possess a spectrum of skill sets in schools, arts, and community settings working closely with all manner of disabled musicians. As the Drake Music website claims: 'Since Drake Music was established as a charity in 1993, we [Drake Music] have provided upwards of 100,000 music-making opportunities for over 1,000 disabled people' (Drake Music 2022f). The success of Drake Music is partly due to their associates having a wide range of expertise. They are able to connect and collaborate internally with fellow associates, and externally with disabled musicians and other relevant parties through one-to-one collaboration, group discussions, and community events. In order for greater progression, Drake Music shares its processes publicly (Drake Music 2017a).

The funding of Drake Music is similar in nature to OHMI with key funders, Arts Council England and Youth Music, as well as with supplementary funding from several trusts and supporters (Drake Music 2022e). As stated on the Drake Music website and confirmed by former CEO, Carien Meijer, the main source of their funding (£200,000 worth, see Meijer personal interview 2022), is from Arts Council England: 'Drake Music is an Arts Council England National Portfolio Organisation and are strategically funded by Youth Music' (Drake Music 2022e). According to the Arts Council England website (2023a), the official amount for 2022/23 was £197,615. An integral aspect of Drake Music's open mentality is collaboration. With research and development for accessible music technology, the collaboration allows disabled musicians to communicate with instrument makers, being manufacturers, hackers, or technologists from the DMLab, to build new instruments (Drake Music 2022p). Drake Music allows these groups of practitioners to become part of the DMLab community, as a forum for the internal communication of their theoretical and practical concepts (Drake Music 2022c). Therefore, communities such as the DMLab need to be established. Another form of collaboration Drake Music provides is support in schools, which has been particularly notable in the South of England through research and development. This can involve: young people devising designs for new instruments and prototypes for testing; the DMLab community presenting their instruments; and teachers testing new inventions and providing their own input (Drake Music 2022o). These targeted

projects presented in localised areas are reminiscent of OHMI's Music-Maker Programme (OHMI 2022h).

Drake Music runs another targeted project called the DM Collective Artistic Development Programme, which, 'aims to change the landscape for Disabled musicians, making a career as a musician more accessible and sustainable' (Drake Music 2022I). The aim of the programme is to develop disabled musicians to have a, 'sustainable portfolio career', with support for these disabled musicians being provided through commissions, mentoring, and residences, along with connecting with the DMLab community (Drake Music 2022h). This scheme gives professional opportunities to disabled musicians through funding, specialised expertise, and collaboration. However, the scope of these projects is limited because Drake Music is only able to assist a handful of disabled musicians. Although it could be argued that this support is more concentrated. In addition, Drake Music provides considerable support in schools and classroom settings by: offering participatory music-making projects across England, as well as sharing their knowledge and expertise through training and consultancy; working alongside schools and music education hubs to offer inclusive activities for people under the age of 25; providing peripatetic lessons, whole class teaching, inclusive ensembles and creative projects; and sharing learning and instrumental resources from within Drake Music's network, allowing for greater inclusion across the music education sector as a whole (Drake Music 2022b).

In 2020, Drake Music set up the Accessible Musical Instrument Collection (AMIC), as part of the DMLab programme. The website claims that: 'Currently, nothing like this exists anywhere in the world' (Drake Music 2022a). I would argue OHMI and May We Help (which will be explored later) have similar schemes in principle. However, the practicalities of the AMIC are more extensive, which would help when presenting this collection to prospective funders. The reason this collection has been created is because disabled musicians need equipment, which suits their needs. As stated on the Drake Music website: 'Access to the right musical instruments and technology can be powerful and transformative' (Ibid.). Furthermore, Drake Music has described what the AMIC will be in glowing terms:

- 'A ground-breaking national collection, representing state-of-the-art of accessible instrument design.
- A world-class resource for Disabled people to explore technological possibilities for making music.
- A focal point for development of cutting-edge accessible instrument technology'
 (Ibid.).

Again, the effusive language is used as self-advertising aimed at potential funders. This should not detract from the fact that the potential of this resource is extensive if musicians and practitioners are aware of the collection. By having devices and instruments together in one place, various practitioners would have a reference point for their own designs and methods in the future to be shared freely. Not only will existing technology be available in the collection, new innovations will also be accepted, from the DIY and experimental, to the expensive and sophisticated (Ibid.). Although the website has a plethora of resources for designers and makers, musicians, and educators (Drake Music 2022m and 2022n), the AMIC is a physical space: 'AMIC will be housed in an accessible space at Drake Music's HQ [in Shoreditch] and will be available to visit' (Drake Music 2022a). Visitors such as musicians, makers, teachers, and academics can test out adapted instruments using an accessible workstation to find the instrument and equipment they need (Ibid.). Former Drake Music CEO, Carien Meijer, did confirm that the collection will be archived online (Meijer personal interview 2022).

In summary, Drake Music is a well-established, interconnected, and expanding organisation. The funding and sponsorships Drake Music receives underpin the costs and resources required to: have personnel on-site in school, arts, and community settings; make instruments available for testing and designing; and provide training for their practitioners. The Drake Music associates and their in-house DMLab community are directly invested and available to help disabled musicians and fellow practitioners who need assistance. However, a potential issue is that the people who need these resources and information are unaware of these reference points. This is because these provisions are mostly available only on their own website, with limited sharing in other music and disability circles. This is not through a lack of ambition because Drake Music is predicated on facilitation for all disabled musicians

with their philosophy of sharing and open-sourcing. An example of this is Drake Music's Accessible Musical Instrument Collection providing an historical, and ongoing physical and online archive for all groups of people interested in seeking out adaptive instruments and devices, and critical information (Drake Music 2022a).

5.1.3 – May We Help and Cincinnati Adaptive Music Camp

The focus of this case study is the Cincinnati Adaptive Music Camp (shortened to CAMC), which is a week-long collaboration run by the Adaptive Music Project. CAMC is described as 'an outgrowth of the Adaptive Music Project, an organization committed to making excellence in music education accessible for ALL' (CAMC 2015). The camp is managed by codirectors Deb Amend who is in charge of the business operations of the camp, and Jennifer Petry (as we have seen, a teacher of students with LDA) who facilitates LDA musicality for children with LDA (Ibid., and Petry personal interview 2018). Part of the origins of this alliance began when May We Help built cello foot stands to allow Petry's armless daughter to play the cello with greater stability (Bonis 2016). CAMC and May We Help (with assistance from Xavier University and Ethicon) collaborated to make adaptive music devices for children with 'limb differences' to facilitate their instrument playing (Ibid., and May We Help 2020c). The main reason this union was viable was because May We Help does not charge for the labour, the use of their facilities, nor the construction of adaptive devices as this organisation has been funded through donations, as well as through several trusts and supporters (Bonis 2016, and May We Help 2020e and 2020h). Jennifer Petry rationalises the amalgamation of May We Help and CAMC:

May We Help was really... integral. I live in Pennsylvania but we had the Camp in Cincinnati... because of them... [May We Help]. There are a number of... engineers or volunteers... We needed numbers; we needed people [who were] dedicated; we needed expertise... Without that, we couldn't really have developed the [adaptive] devices (Petry personal interview 2018).

Valerie Thomforde, a musician with LDA and advocate for teaching musicians with LDA, was asked to teach at the camp. Thomforde discusses the benefits of this in-person collaboration:

I worked at [CAMC] ...for one year and that was brilliant... Specifically to bring together engineers and music teachers, ...and... that's the issue. Music teachers are not engineers and engineers don't know enough about music. You really need both to come up with solutions, ...I thought that was a really great idea that Jennifer [Petry] had ... There was the right knowledge base there... to come up with something that worked (Thomforde personal interview 2022).

Tony Memmel, a musician with LDA and advocate for helping children with LDA, was requested to teach one of CAMC's students. Memmel provides another reason why the camp was based in Cincinnati:

Cincinnati was the place, to my recollection, that they [Adaptive Music Project] decided to do it because one of the other leaders, Deb Amend... her family was based there. They had just connections at local colleges and universities where they could have space and dormitories... for the students (Memmel personal interview 2020).

These connections include Cincinnati-based organisations, Xavier University who were able to rapidly prototype the manufacturing of adaptive devices through 3D-printing and provided a performance space for the musicians, and employees with prosthetic experience from Ethicon (Bonis 2016 and May We Help 2020c). It is fortuitous that Amend and Petry were able to find a hub in Cincinnati for in-person collaboration. However, in-person collaboration is difficult (beyond a week-long camp) because this requires all practitioners to gather at a single location, which is a time-consuming, expensive, and arduous process, if they do not live locally. This is more apparent for a country with the land mass of the USA.

May We Help was founded by three engineers with the aim to create individual devices for disabled people in their daily lives (May We Help 2020f). Its mission is to 'design and create

unique custom solutions for individuals with special needs', with a vision '[t]o see all individuals with disabilities have the opportunity to gain independence and pursue their passions' (May We Help 2020a). The organisation has a diverse infrastructure from many sectors, comprised of relevant personnel and experts. The May We Help team has over 75 volunteers consisting of 'engineers, industrial designers, inventors, welders, woodworkers, seamstresses, doctors, occupational and physical therapists whose skill sets come together to design, build and deliver custom devices at **no cost** to hundreds of recipients every year' (Ibid.).

Organisations can contribute to collaboration using suitable experts, as this will inspire other specialists and further fields to find individual solutions. As an organisation, May We Help has recognised the value of occupational and physical therapy as part of the device-making process. In order to find the best PTs and OTs, May We Help provide local listings in order for the individual to make their own decision of which therapist best suits their needs (May We Help 2020g). Thomforde has had experience of others using occupational therapy during her time at the organisation, Helping Hands (similar to May We Help's Adaptive Equipment Swap):

[At] the Helping Hands gatherings ... little babies with limb differences, do have OT services and PT ... I think for other kids, it's hugely beneficial ... especially with foot users. I know a friend of mine who is missing both her arms [used] OT and PT for years ... She learned to use her toes as individually as she does ... I never had any of that. My piano teacher [wasn't] ... trained in any kind of therapy. She was just a really caring piano teacher (Thomforde personal interview 2022, see Thomforde 2019).

Although some armless musicians may be able to learn by themselves or with the intervention of teachers (like Petry for Dennehy), occupational and physical therapists may be able to identify some of the issues which could be faced by these particular groups of musicians.

With the individualised music-making of musicians with LDA, multidisciplinary collaboration and communication between occupational and physical therapy and other fields is required (Kielhofner 2005, p.491-493, Bailey 1986, p.27, Paul and Ramsey 2000, p.112-117, and Woldendorp and van Gils 2012, p.236). Carien Meijer, former CEO of Drake Music, explains that Drake Music does not collaborate with the fields of occupational and physical therapy, but the potential is there:

Very rarely, to be honest. So, we have done some work in hospital settings. I think there's scope for doing more. It's not an area where we've really put a lot of our focus. And that may be partly because we don't have those networks or the expertise internally ... In terms of working with therapists ... there is sometimes externally an expectation that we provide music therapy, which we don't ... We've got all kinds of workshop leaders, musicians and so on ... [who] happen to train as therapists. But our work, although it has therapeutic benefits ... it's about access to music-making (Meijer personal interview 2022).

For the development and rehabilitation of affected limbs and digits or through the use of alternative limbs e.g., feet supplanting hands, occupational and physical therapy can connect musical and everyday activities. If different practitioners such as doctors, prosthetists, device and instrument makers, musicians, and teachers had a greater understanding of the benefits of occupational and physical therapy, then this would only benefit musicians with LDA in the long term. These benefits would not just involve instrumental facilitation and musicianship. The act of playing a musical instrument can act as pain relief and body wholeness, which could cross over into applicable areas of rehabilitation and therapy.

The wide-ranging, localised, and voluntary team of May We Help presents a model for greater collaboration across numerous fields to assist disabled musicians. To complement May We Help's devices translating to music, solutions for music and disability can potentially be translated to other forms of physical disability in other aspects of life. The role of May We Help highlights how more disability organisations should expand beyond

their own areas of expertise, where possible. May We Help was willing to experiment with practitioners in the field of music and disability to expand the usefulness of their designs.

The timeframe May We Help give for building a device, 'varies greatly' (May We Help 2020g). For CAMC, this entire process of building assistive equipment and its musical application lasted only one week (see Petry personal interview 2018). Petry describes the device building process and the rationale for CAMC's existence:

Every year, we [the collaborators] come up with a new iteration [device] ...that makes it easier and better... I would say the [revision] process takes a lifetime, but I would say the initial process probably takes a year or two to get a... working prosthetic... The other thing is usually the prototype is not helpful. Often, it is frustrating and a waste of time and those are just the facts. It's why we have our camp: to go through that prototype process in a condensed manner... Sometimes, you work and work and work with a prosthetic and then you realise, 'Hey, I don't even need this' (Ibid.). 15

This highlights some of the issues of the trial-and-error process addressed in the previous chapter. However, because the construction of a prototype is concentrated over a week, the musician during their time away from the camp can understand what does and does not work. The collaboration of May We Help's engineers and CAMC's teachers, along with parents and children using the adapted device is exceedingly important and deemed paramount by all parties.

Petry elaborates on the difficulty of the initial process of building these devices:

We [the collaborators] spent quite a bit of time the very first day... Ideally, it's an hour with each child that first day... They [the engineers] developed the device based on that meeting, and then they bring it in the next day and it's never right.

¹⁵ Upon review, Petry stated that the term 'revision' was more applicable compared to 'prototype' (see Ibid.).

Sometimes it's so way-off base... and then they go from there and they build another one (Ibid.).

A further issue is that the volunteers have to give up their free time during this week:

Occasionally, there have been one or two engineers; ...they just took the week off work... There were some companies that gave them a day or two off [work] and actually paid them anyway, as if they were working, and they called it a donation (lbid.).

Despite having the expertise of May We Help, there are differences between having a prototype for everyday activities versus the intricacies of prototypes to facilitate music-making. These volunteers do not specialise in the dexterities required for the aesthetic control and expression of playing a musical instrument with LDA, which differs greatly from other everyday solutions, which the engineers are more attuned to. These problems are exacerbated due to tight deadlines and several volunteers being unable to dedicate all their time to producing these devices. For other building projects, the volunteers can take their time with longer deadlines (see May We Help 2020g).

One of May We Help's projects which is similar to the other music and disability organisations I have discussed so far (OHMI's Instrument Hire Scheme and Drake Music's Accessible Musical Instrument Collection), is the Adaptive Equipment Swap (May We Help 2020a). According to May We Help's website: 'In 2019 alone, over 250 people were matched with over one million dollars worth (sic) of life-changing adaptive equipment – at no charge' (Ibid.). This project demonstrates how worthwhile and successful funding has helped numerous people. If the full costs of this equipment (approximately \$1,000,000) had been passed onto the recipients, this would average \$4,000 per person. As \$4,000 could equate to the cost of a high-end musical instrument, the same cost for adaptive equipment would not be plausible for most people. This project further emphasises May We Help's model for local, internalised collaboration in order to help disabled people as best they can. Within May We Help's headquarters, Aspire Therapy Services lead therapist, Lisa Davison, is part of these swaps, 'to ensure that your equipment match is appropriate, comfortable and

provides the best functional outcome' (May We Help 2020b). Furthermore, these OT and PT services are used for 'collaboration and consultation' on a case-by-case basis, as this process gives the May We Help volunteers, 'a clear understanding of the individual's medical considerations, functional goals, positioning needs, and prior equipment use' (May We Help 2020g). As discussed in chapter 4, occupational and physical therapy has value for adaptive living in general, which can extend to LDA musicality.

In summary, the synergy between May We Help and CAMC means that positive improvements can be made in building devices across the spectrum of disability (which music fits within), due to having concentrated, in-person communication. However, the main challenges of the partnership are the project has to be undertaken within such a short timeframe, meaning the processes are necessarily rushed and the volunteers may be working extended hours beyond their regular work schedule. If CAMC could collaborate remotely beyond the week-long window, the musicians, teachers, and engineers may have more success, as the time constraints are reduced. The collaboration suggests that the combination of devices for everyday use and music can be intertwined in order to provide better, quicker, and more effective solutions in the future. If this link is identified, then collaboration between different practitioners across many fields is more likely. For example, May We Help recognised the value of intervention from occupational and physical therapy (May We Help 2020b and 2020g).

May We Help's objectives and practices provide a framework for in-person collaboration and communication. May We Help has the nucleus of Cincinnati to facilitate local, concentrated communication and collaboration of experienced volunteers with a plethora of experience. Volunteers are funded for their contributions, yet as the CAMC coalition proves, these volunteers have regular jobs, with May We Help as a side project (see Petry personal interview 2018). This indicates that May We Help is unlikely to obtain the funding to pay these volunteers a full-time wage to work for the organisation. The well-funded Adaptive Equipment Swap is a good model for providing equipment to individuals (see May We Help 2020a). However, the information concerning how these devices are made and used is not publicly available. Ultimately, the design and function of any piece of equipment could be passed onto other swap projects or organisations such as OHMI's Instrument Hire

Scheme (OHMI 2022e) and Drake Music's Accessible Musical Instrument Collection (Drake Music 2022a) and vice versa. May We Help and CAMC as a collaboration suggests that music and disability provisions expand into societal disability provisions in a mutually beneficial relationship. However, due to geographical distancing, organisations and individuals need to have these conversations and demonstrations online, particularly if communications across numerous fields are to improve in the future.

5.1.4 - Can-Do Musos

The origins of Can-Do Musos took place in 2013 when three disabled drummers—Andrew Hewitt, David Segal, and Mike Mignogna—attended 'Drumming's Global Ambassador' Dom Famularo's Wisdom Drumshed at Port Jefferson, New York (Can-Do Musos 2017a). The four of them became founders of the organisation when they discussed the difficulties of being accepted as a disabled musician, and the lack of opportunities compared to their ablebodied contemporaries (Ibid. and Segal personal interview 2020). The tagline for Can-Do Musos is to be: 'A Global Voice for Disabled Musicians' (Can-Do Musos 2017e). The name 'Can-Do Musos' comprises of two parts. The first part refers to having a 'can-do' attitude, with the second term 'musos' describing passionate musicians dedicated to music (Ibid., and Segal personal interview 2020). The rationale for this name was the founders sought a name that would stand out from coalitions and organisations (Segal personal interview 2020). The unusual name of 'Can-Do Musos' suggests informality and accessibility by serving disabled musicians in pursuing their musical passions. This ethos is more befitting of popular music sensibilities rather than classical music, which has greater barriers to entry, particularly for disabled musicians (see Lubet 2019, p.317-320). Co-founder, David Segal provides an anecdote, which encapsulates Can-Do Musos' ethos:

I think we're putting the demand out there... There's some sort of untapped talent out there in the musical world for... disabilities... When you're disabled, you always think you're alone... I've found five drumming brothers that all have arthrogryposis [a number of conditions which affect the joints] ... We met this girl... she actually has a form of arthrogryposis... and her dad...said: 'What I like about your organisation... [is] you have an attitude where you aim big... It's not like with other organisations...

They've been like pity parties'. You ain't gonna (sic) get that from us (Segal personal interview 2020).

The aversion to being part of a 'pity party' has its place in popular music with the protest songs of Johnny Crescendo and Ian Stanton (see Cameron 2009).

The four founders are the organisation's Board of Directors and are all experienced, influential drummers (Can-Do Musos 2017a). In addition, Can-Do Musos has: Associate Board Members, an International Advisory Board with a community of drummers with influence in the music industry, and advocates for Can-Do Musos' practices including consultants, speakers, educators, and clinicians (Ibid.). The range of expertise and Can-Do Musos' global reach means the organisation can provide resources and advice to their specific members. Can-Do Musos is funded by donations, mostly through a tab on their website (Can-Do Musos 2017e). A significant milestone occurred in March 2018 for Can-Do Musos when they became a 501c3 registered, not-for-profit charity meaning donations are tax deductible (Can-Do Musos 2017d, and Segal personal interview 2020). Additionally, a useful connection for the organisation was the fact that Segal has family ties to the investment sector: 'My [Segal] dad's an investment banker... So, I've been able to reach out to people that are investors and they've contributed' (Segal personal interview 2020, see Can-Do Musos 2017d). Can-Do Musos shares its funds with disabled musicians for various in-house and external collaborations. In our interview, Segal discussed how some of the funding has been used:

The last five or six years, we've performed at the NAMM [National Association of Music Merchants, hereinafter NAMM] show and had a panel of disabled musicians. One of... the primary ways is we fly somebody into California, take care of their hotel room and get them into the [NAMM] show... They're [disabled musicians] able to connect with a lot of top people in the music industry (Segal personal interview 2020).

Can-Do Musos' presence at the aforementioned NAMM shows has been highlighted proudly on Can-Do Musos' website (see Can-Do Musos 2017b). NAMM is one of the music-making

industry's most prominent annual events for musicians, instrument and device makers and designers, and well-known industry figures (NAMM 2023). Segal states how Can-Do Musos members have gained professional work by networking with directors and endorsers at NAMM, as well as through the Can-Do Musos website (Can-Do Musos act as an intermediary):

One of the [Can-Do Musos] members who lives out in California. His name is...

Geno... and he's a drummer... [with] the same disability that I have, which is called arthrogryposis. When he [Geno] was out with us the first time, we had a commercial director who's done movies and commercials... People have gotten... endorsement deals from there... We've also become a referral source: almost like a casting agency. A lot of directors have used our website to find people... All the money is for them [Can-Do Musos members] ... we [Can-Do Musos] haven't gotten a percentage (Segal personal interview 2020).

Due to Can-Do Musos being a 'referral source', the organisation is able to operate with fewer running costs, hence why the organisation is able to help disabled musicians through donations rather than relying on the aid of funding bodies. In order for Can-Do Musos to be 'a global voice for disabled musicians', the organisation utilises its website, events, collaborations, and projects to provide disabled musicians the network opportunities to expand their professional profile and portfolio. If Can-Do Musos is unable to help directly, they find the right people to contact in order to help their members (Ibid.). Examples of projects featured on the website are: the Can-Do Radio Show and Can-Do Musos TV featuring music, gigs, and interviews from their members, and music videos from any musician living with disability, hosted by Can-Do Musos co-founder Andrew Hewitt; the first-ever Can-Do Musos Music Festival, which is a '2 1/2 hour show featuring 60 musicians from 20 countries'; and a featured affiliation of South Korean group 'ArtWeCan', a support network for disabled artists with a collaboration of members from both groups (Can-Do Musos 2017e).

One of Can-Do Musos' most important projects was when several members were part of the 'Yes I Can' campaign, including a music video to promote UK television network, Channel 4's coverage of the 2016 Rio Paralympics (Ibid., and Channel 4 2016). The music video combines disabled athletes in action, along with disabled musicians playing musical instruments (Ibid.). According to Can-Do Musos' website, of the ten Can-Do Musos members featured, six have LDA (Greg Anton, Bill Clements, Neill Duncan (1957-2021), Mark Goffeney (1969-2021), Alvin Law, and Marc Playle) (Can-Do Musos 2017e). The Can-Do Musos members were flown out to the famous Abbey Road Studios in London to record a cover version of Sammy Davis Jr's *Yes I Can* (1964) (Ibid., and Segal personal interview 2020). Segal describes this project as:

One of our [Can-Do Musos] proudest moments... We [Can-Do Musos] were contacted by the BBC [correction: Channel 4] in 2006 [correction: 2016] ... They [Channel 4] flew ...eight to ten members out on their dime to Abbey Road Studios to perform this great song and production of *Yes I Can* (1964) ... People [members of Can-Do Musos] are still getting work because of that commercial (Segal personal interview 2020).¹⁷

Another reason Can-Do Musos is able to operate without the funds obtained from a funding body is because companies, such as Channel 4, are willing to cover the expenses for disabled musicians to be employed for its projects. Saxophonist with LDA Neill Duncan, a member of Can-Do Musos and a musician employed for the 'Yes I Can' project, attests to Segal's previous statement: 'in some ways, I'm getting more work now than I was getting... It's just opened a whole new thing because now I'm advocating for people with disabilities' (Duncan personal interview 2018a). The 'Yes I Can' commercial is a strong indication of Can-Do Musos' influence as an intermediary for significant music and disability projects. This particular advertisement provided a national (and international) platform for several musicians with LDA, by combining music and sport via the Paralympic games.

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¹⁶ This campaign encapsulates the overcoming narrative in both sporting and musical contexts (see Silva and Howe 2012, p.175 and Buck 2023, n.pag.).

¹⁷ Upon review, Segal stated that the excerpt should be 'eight to ten members' rather than 'ten members' only (see Ibid.). Can-Do Musos' website does state the number as ten (see Can-Do Musos 2017e), however, I respected Segal's wishes.

Another form of promotion occurs on the Can-Do Musos website, with each musician (or band) having a personal biography with links and videos of their most significant works (Can-Do Musos 2017c). I asked Segal about the process of putting each member's biography on Can-Do Musos' website:

We [Can-Do Musos] tell them [the musician] to send what they have and we make recommendations to them... If they don't have a proper biography or video, ...we give them all kinds of advice on what to put in it. We said, 'use this person as a template for what to include'. So, we'll work with them and our goal is to make the best page possible for them (Segal personal interview 2020).

The biographies are another avenue, which facilitate the networking and promotion of disabled musicians. This practice centralises disabled musicians' credentials from other places on the Internet into a single biography, and has the potential to enable commercial directors to scout a specific musician they wish to work with professionally.

In summary, Can-Do Musos has numerous useful professional connections, particularly through co-founder Dom Famularo's influence in the music industry (Can-Do Musos 2017a). Furthermore, co-founder David Segal's father is an investment banker, meaning he had the financial acumen and connections to assist Can-Do Musos in becoming a not-for-profit charity (Can-Do Musos 2017d and Segal personal interview 2020). As a growing organisation, their objectives, remit, and funding will expand allowing for more collaboration and the professional benefits for musicians with LDA (and other disabled musicians). Additionally, Can-Do Musos has fewer operating costs due to: having no physical headquarters; acting as a conduit for their various practices; and having their costs offset for certain projects such as the 'Yes I Can' commercial (see Segal personal interview 2020). For provisions involving instrument and adaptive music-making, there may be other organisations which are more directly involved, although Can-Do Musos again can act as an intermediary. Can-Do Musos is an international support network, with great potential for connecting disabled musicians to the people they need. This is seemingly apparent with their 364 global members (musicians and bands) from 36 countries, as of writing this section

(Can-Do Musos 2017c). Although this is laudable, there must be thousands of disabled musicians who are unaware of Can-Do Musos' intermediary support.

5.2 The perspective from UK music education hubs

Before investigating the surveys of the music education hubs, a music education hub needs to be defined. Arts Council England (2023b) defines these hubs: 'Music Education Hubs help children and young people access music education and develop their musical interests and potential'. Music Education Hubs are led by a person called the 'Hub Lead' who oversees these practices and the partnerships with schools, local authorities, community music organisations and projects within their local area (Ibid.). Various practitioners across music-making including teachers, technologists, and instruments makers and designers assist and oversee the children and young people (Ibid.). With OHMI's speciality in adaptive instrument-making such as the prospect of 3D-printing the one-handed clarinet, they have collaborated with their music hub partners and have acknowledged the vital roles of: 'Northamptonshire Music and Performing Arts Trust (NMPAT), Nottingham Music Service and for the first time, Services for Education in Birmingham' (OHMI 2023). For Drake Music's ambition of using accessible instruments within music education settings, they oversee the Think22 programme, which includes hubs from Essex, Newham, Coventry, and Tower Hamlets, with a view to expanding beyond these numbers (Drake Music 2023).

The first question I asked the respondents was: 'Could you give a brief overview of the infrastructure of your hub?' The Ealing Music Service and Devon and Torbay Music Education Hubs operate using two contrasting models. The Ealing Music Service adopts a more traditional model for their hubs through employing and contracting the right people. The Ealing Music Service is the Lead Organisation of the Music Education Hub for Ealing and, as Yogesh Dattani states, comprises of approximately 50 people including: '1 head of service, 2 deputies (both 0.5fte), 1 business manager, 2.5 admin staff, circa 45 teachers', and: 'The governance structure comprises a range of stakeholders' (Dattani personal survey)

¹⁸ It was in fact the Teignbridge and Torbay Music Lead, Tom Deam, who described this structure (see Deam personal survey 2023).

2023).¹⁹ In contrast, Devon and Torbay Music Education Hubs adopt, 'a commissioning model, so we work with and support other partners, schools, teachers, self-employed Visiting Music Teachers (VMTs)' (Deam personal survey 2023). Both of these models have the potential to link up with music and disability organisations for musicians with LDA in their local areas.

Based on collaborations and projects operated by UK-based Drake Music and OHMI, the commissioning model is more conducive for connecting locally with the musicians with LDA they support. This is because practitioners at Drake Music and OHMI could be commissioned for projects where they are needed. However, this is not to say that the traditional model does not have its place. For instance, even if OHMI and Drake Music sent a musician a hired adapted or accessible musical instrument, the methods for teaching the instrument would need to be communicated to the local teacher. Therefore, the staff from the music and disability organisations may be contracted to do this. Despite this, the overriding issue is that it is likely that Drake Music and OHMI would need to send their experts from London and Birmingham around the UK. If this information could be centralised, the practitioners in a hub would have better access to tools and resources allowing their own employed or locally commissioned teachers to have the knowledge for teaching a student with LDA.

As I wanted to understand the type of projects involving disabled musicians these hubs oversee, I asked the second question: 'Could you provide examples of collaborations your hub has made/is making with other organisations/hubs/people to assist disabled musicians?' Both hubs have collaborated for projects involving SEND students in education settings providing access, equipment, personnel, and facilities. For the Ealing Music Service:

We [Ealing] encourage our partner organisations to work with children and young people with special educational needs and disabilities (SEND). For example, one local opera company is currently working with children with SEND in mainstream schools.

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¹⁹ Upon review, Dattani clarified the set-up of the Ealing Music Service, as mentioned before the quotation (see Ibid.).

We have 6 special schools and our SEND Music Consultant supports each one on a rota basis and, in addition to this, we work with a range of partners to further enrich our offer, for example, with national partner organisations, Live Music Now and the Orchestra of the Age of Enlightenment and local partner organisations, Ealing Youth Orchestra and the Ealing Symphony Orchestra (Dattani personal survey 2023).²⁰

For the Devon and Torbay Music Education Hubs:

Current project: In collaboration with the SEND support team, Devon County Council, aimed at children with physical disabilities in mainstream education. So far this project has involved one day practical group music making workshops in different areas of Devon. Individual participants have availed of the offer of follow-up visits by me [Deam] to address compatibility and accessibility of instruments. Follow-up work will also aim to work with VMTs [Visiting Music Teachers] to enable them to give effective and meaningful instrumental lessons. Next stages include creating regular accessible ensemble playing opportunities for children with physical disabilities, working with existing Hub funded ensembles to help them remove barriers and provide access, and support schools to ensure that music opportunities are equitable and accessible (Deam personal survey 2023).

Clearly, these hubs are in tune with the needs of the children, teachers, and expertise available within their hubs geared towards SEND. SEND provisions cover a wide-range of different needs, with LDA musicality being a small part of disability music-making, potentially even having very few musicians or possibly not encountering a single musician with LDA. The Devon and Torbay Music Education Hubs are attempting to introduce a process and protocol which matches instruments for students to hire, and potentially adapt the instrument, through the hub:

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²⁰ Upon review, Dattani requested the inclusion of the words: 'national partner organisations' as well as 'and local partner organisations, Ealing Youth Orchestra and the Ealing Symphony Orchestra' (see Ibid.).

We are in the process of introducing a system to enable / require schools to identify children with physical disabilities in classes for whom class sets of instruments have been hired from the Hub. This includes children who may not be on the SEND register. One of the Hub Team can then, if necessary, carry out an assessment to ensure that the instrument is compatible in its standard form, and if not, adapt or source an appropriate instrument and support the teacher to ensure that the child has an equitable and meaningful experience (Ibid.).

If a musician with LDA studying in the Devon area or a local teacher could be directed to the OHMI Instrument Hire Scheme, they could provide the person making the assessment with a hired adapted instrument to facilitate their LDA musicality in school settings. In terms of support beyond the hub, 'The Hub [Devon and Torbay] funds and supports a number of Hub Funded Partners which can call on additional support in ensuring that activities are accessible to children with disabilities' (Ibid.). With Arts Council England's possible decrease in the number of music education hubs from 116 to 43 through merging areas (Musicians' Union 2023), these connections could potentially provide a more efficient approach. Conversely, as these projects and collaborations will be less concentrated in localised areas, the hub's processes, expertise, and resources may leave more disabled musicians to be overlooked. Additionally, music is usually not perceived as a core subject:

When cuts are made, allegedly superficial or 'extra' programmes such as music are often the first to go. While this might be claimed to be among the least damaging means to cut spending, the impact on culture and values may be far more than is typically reshared (Lubet 2011a, p.64).

Most of the musicians with LDA I interviewed and studied in chapter 4, typically described how they had to use their own initiative when finding their own methods for playing a musical instrument, or creating their own adaptive prosthetic device. Several musicians with LDA went through the trial-and-error process by themselves or through fortunate local connections, which are not widespread and have been concentrated for their specific needs. Therefore, the final question I asked the respondents was: 'If a disabled musician approaches your hub, what information/resources/provisions/advice could your hub

provide to suit their needs?' Based on the responses, it is apparent that music education hubs do want to be of assistance to all disabled musicians. However, an issue may be that the number of musicians with LDA who approach these music education hubs are few and far between. Although asking this question may seem to run counter to the purposes of music education hubs, part of the problem for musicians with LDA is that the support they receive is mainly from within the hub such as through school bands and group ensembles.

Deam provided information about a wealth of support his hub provides across the spectrum of music and disability:

They [the disabled musician] would be offered bespoke support needed to address unsuitability of the standard provision, e.g.

- Signposting to a wide range of musical opportunities, and a wide range of hire instruments.
- Adapted or alternative instruments, adapted in our workshops by one of our technicians, or hire from the OHMI Trust ...
- Support for their teachers, school, and local Hub funded opportunity in meeting the needs of the child (Deam personal survey 2023).

It is encouraging that the Devon and Torbay Music Education Hubs are in a position to provide the advice, support, personnel, and connections. It would be interesting to see how many musicians with LDA within their local area would be privy to the connections and infrastructure their local hub has to offer in order to support them for their specific musical and performative needs. During Dattani's tenure, his hub has not been contacted directly by a disabled musician. However, Dattani also states that he would like to support disabled musicians more so than they already do (see Dattani personal survey 2023). This is captured in Dattani's response:

In my 22 years at Ealing Music Service (as head of service since January 2004), I don't recall any disabled musician having approached the music hub. I would like to become more effective... [in] seeking out disabled musicians in need of support.

There was one occasion when one of my senior colleagues faced a situation in which one of her violin pupils had the last digit [correction: phalange] of their thumb missing and, therefore, could not defy gravity to hold the bow up. I contacted The OHMI Trust who promptly sent me pieces of equipment that would compensate for the missing digit and the child was able to participate in violin lessons (Ibid.).²¹

Although it is encouraging that both Deam and Dattani are aware that OHMI is *the* organisation for LDA musicality (due to being tailored for this niche area of physical disability), this information needs to be conveyed beyond classrooms and group ensembles. Many provisions used by OHMI and through these settings are geared towards the orchestral family of instruments primarily, rather than the DIY musicality inherent with musicians with LDA playing instruments associated with genres of popular music (see Lubet 2019, p.317-320).

In summary, this investigation has provided a fascinating insight into two UK-based music education hubs, which have the potential to assist musicians with LDA through their association with relevant music and disability organisations, chiefly OHMI for LDA musicality. Both of these hubs have the personnel, advice, support, connections, and access to equipment and facilities in classroom settings, be it through the traditional model of employing or contracting relevant parties or the new commissioning model, which can assist musicians with LDA with a more concentrated approach. Typically, these hubs cover a wide range of SEND, which has highlighted useful projects, assisting a number of disabled musicians. Although LDA does fit within SEND, LDA musicality is a distinct, concentrated, and rarely uncovered area of interaction for the average UK-based music education hub. It is evident that Tom Deam and Yogesh Dattani have vast experience and knowledge of the right people to contact and collaborate with in order to help musicians with LDA, be they approached directly or through connections within their own hubs. Both of them were aware of OHMI's existence and that the organisation could directly assist musicians with

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²¹ Upon review, Dattani requested the word 'needs' to be changed to 'need' as well as the word 'and' to be changed to 'to' (see Ibid.).

²² Drake Music and OHMI are listed as partners of Ealing Music Service on their website (Ealing Music Service 2023b).

LDA. However, the issue is that those less qualified and/or personnel without the correct knowledge who work for them would be unsure how they could assist a musician with LDA.

Another issue is that outside of classroom settings and group ensembles, the average musician with LDA is unlikely to know where to get advice, support, and equipment which can assist their adapted musicality. A particular illuminating example discovered in this examination is that despite being willing to help, in his 22 years at the Ealing Music Service, Dattani was unaware of a single disabled musician having approached the music hub (see Dattani personal survey 2023). Dattani admits this is a gap and would like to remedy this (Ibid.). Furthermore, if a musician with LDA did approach his hub, Deam had the confidence to signpost a musician with LDA to hire an adapted instrument from OHMI, as well as include their own personnel, contacts, technicians, and workshops to be utilised for adapting instruments (see Deam personal survey 2023). It is worth mentioning that Dattani recognised OHMI had the resources to help, when required (see Dattani personal survey 2023). It would be interesting to know whether these service leads are the exceptions to the rule.

5.3 Discussion surrounding organisational support

Three of the four music and disability organisations examined (excluding Can-Do Musos) provide many of their practices in-person. When referring to services, this includes projects and collaborations involving employees, teachers, and volunteers working directly with musicians with LDA and disabled musicians in general. Despite a more indirect approach, Can-Do Musos plays a vital role in promoting disabled musicians and allowing them to network with prominent people in the music industry. However, it could be argued that in certain facets of their operations, the founders use a direct approach by appearing in person and provide platforms for disabled musicians including the NAMM shows, the Can-Do Radio Show, and the Can-Do Music Festival (Can-Do Musos 2017b and 2017e). Regarding the personnel employed by these organisations, the infrastructure is typically dictated by their practices. OHMI, Drake Music, and May We Help (on behalf of CAMC) have many volunteers and experts interested in the delivery of numerous projects and local collaboration (see

OHMI 2022i, Drake Music 2017c, and May We Help 2020h). For Can-Do Musos, they employ an International Advisory Board of practitioners with a range of expertise, who are ready to assist and use their music industry reputation to promote its members (Can-Do Musos 2017a).

A common strand which surrounds the provisions and practices of music and disability organisations is the classical bias, which these organisations adopt (see Lubet 2019, p.317-20). As a field, classical music strives for technical and corporeal 'perfection' and values virtuosity over facilitation, which may provide further barriers to entry for musicians with LDA (see Lubet 2004, and Howe 2016, p.196). Regarding OHMI, several of their projects are geared towards orchestral instruments, or those which emulate the aesthetic control and expression of traditional, orchestral instruments. In particular, through the OHMI Competition, OHMI works more closely (in terms of funding and resources) with the competition-winning devices and instruments rather than the designs that do not win. A reason for the classical bias in this sense is that, although the judges are experts and/or musicians with LDA, many are classically trained (OHMI 2022b). The classical bias of OHMI is understandable because co-founder Stephen Hetherington has a background in opera, as well as his daughter, Amy being a trumpeter (see Hetherington personal interview 2018 and BBC News 2013). However, it is worth noting that OHMI do provide adapted instruments outside of the orchestra family and instruments (OHMI 2022e). Furthermore, bringing these designs together in one place such as the OHMI website and the 2018 OHMI conference (which took place at a space typically used for classical music, Royal Birmingham Conservatoire) facilitates adaptive music-making being promoted and presented to numerous practitioners across music and disability.

For CAMC, co-founder Jennifer Petry (who ran the practical side of the camp) has a classical bias, due to her background and expertise in running an orchestral academy locally, which she applied to her own teaching of children with LDA (see Petry personal interview 2018). Furthermore, the week-long collaboration ended with a recital utilising Edgecliff Hall at Xavier University in Cincinnati (Bonis 2016, and May We Help 2020c). It is worth noting that not all of the instruments played at the camp were typical orchestral instruments: indeed, Memmel was requested to teach the guitar to a student there (see May We Help 2020c, and

Memmel personal interview 2020). Classical music sensibilities can be useful for translating to future popular music instrument playing such as was the case for George Dennehy (Dennehy personal interview 2021), Mark Goffeney (Schlatter 2017), and Alvin Law (Law 2015). Alternatively, if a musician with LDA is not interested in orchestral instruments or classical music, they may be deterred from playing a musical instrument in popular music or music-making entirely. Drake Music has similar objectives and practices to OHMI, which can involve classical music such as The OrchLab Partnership (involving accessible musical instruments and technology) with the London Philharmonic Orchestra (Drake Music 2022i). However, Drake Music's inclusion of accessible technology and the emphasis on facilitation is a significant difference. Both OHMI and Drake Music have schemes to support teachers of accessible and adapted equipment and instruments (OHMI 2022h and Drake Music 2022g). Out of the four music and disability organisations examined, Can-Do Musos is the most geared towards popular music practices by allowing disabled musicians to promote and network, but not excluding classical musicians. Even the name 'Can-Do Musos' is a quirky term. The 'can-do' provides an informal slant and part of its simplicity, and 'musos' is associated with passionate popular musicians, moving into accessibility and pragmatism.

The surveys of Ealing Music Service and Devon and Torbay Music Education Hubs show evidence of a potential wealth of support for music and disability through schemes, which incorporates collaboration within their own hubs and through the intervention of organisations such as Drake Music and OHMI, where applicable. Although it is useful that community music involves group ensembles and classroom inclusion, a classical bias exists within their most prominent projects (see Deam personal survey 2023 and Dattani personal survey 2023). Another issue may occur in the future when the number of music education hubs could reduce from 116 to 43 (Musicians' Union 2023). This streamlining may allow for expertise, personnel, and resources to be spread more widely across a region. However, currently, the partnerships between OHMI and Drake Music and the respective hubs around the UK is mixed with certain areas being more prepared for LDA musicality than others (Drake Music 2023, OHMI 2023, and Ealing Music Service 2023b). There is a movement towards helping individuals as well with OHMI Music-Makers Individual Scheme (OHMI 2022h), and Drake Music using peripatetic one-to-one music lessons (Drake Music 2022k). Schools are aware of music education hubs, yet there is little information for musicians with

LDA or private teachers outside of these circles. However, if a child wants to learn privately and a music education hub could assist them, the potential musician needs to be aware of this level of support. Furthermore, although it is a US example, when Memmel sought to get private guitar tuition, both Tony Memmel and a local guitar teacher did not believe that a one-handed guitarist could learn or be taught the guitar:

He [the teacher] said: 'That's really cool that you want to learn to play but I don't feel qualified to teach you, so you might be on your own'... It didn't make me angry or anything ... that figures because ... I've never seen it before [a guitarist with one hand] either (Memmel personal interview 2020).

Petry, an experienced teacher of children with LDA, gives several responses she has heard when a teacher is asked to teach a child with LDA, which is in keeping with Memmel's experience:

[It] really depends on how much they're [the teachers] on board ... most teachers will not start ... [with] a child with a limb difference. They just say ... 'I'm not going to do that. That's not my area of expertise. That's not what I went to school for. That's not what I've done for years and years. You need to go find somebody who knows what they're doing.' Well, somebody who knows what they're doing is so rare (Petry personal interview 2018).

In order to break down the barriers of entry for teachers of students with LDA, there needs to be access to information to make the teaching process easier for both teachers and students. Although Memmel was able to learn from books and listening to music (see Green 2002 and Memmel personal interview 2020), having dedicated instrumental tuition may have provided him with better training.

Dennehy explains how it was serendipitous that he had a driven, local teacher who was able to help him learn, describing Petry as 'one-of-a-kind' (Dennehy personal interview 2021):

I [Dennehy] had the most amazing teacher [Petry] ...our family knew just through our town and our small church ... She kind of had her own teaching academy ... and she agreed to teach me too, knowing that it'd be a challenge ... But she was persistent and ... she wanted to teach herself first and she realised that it could be done: with the cello laying ... on the floor and holding the bow with one foot and doing the notes with the other foot (Ibid.).

This demonstrates the great lengths Petry was willing to go to, to teach Dennehy and translate these methods onto the next group of musicians who play with their feet. Not only is it key to have a dedicated teacher for LDA, the student needs to be just as dedicated to persist and succeed. Therefore, the teacher needs to be willing to think differently and spend tremendous amounts of time and effort collaborating. It is understandable why many teachers may feel overwhelmed or are unwilling to start with a student with LDA.

Thomforde, through her website, 'Another Way to Play' is essentially a consultant for music teachers who want to learn about adaptive music-making, and device and instrument building (Thomforde 2019). Thomforde explains her status as well as providing some advice based on her experiences as a student and a teacher:

Oftentimes other teachers will reach out to me asking for ideas and solutions for their students ... I do emphasise ... that everybody is different. And the goal is really to figure out how to use your body most effectively ... I do think finding individualised solutions is really the best way to go, even though that is trickier, especially when it comes to customised instruments ... I think that will allow the musicians to get further (Thomforde personal interview 2022, see Thomforde 2017a and 2019).

Although it may be the inclination of most teachers to use their tried and tested methods for all students, it is clear that both parties benefit when they are receptive to investigating new ideas. Furthermore, despite (according to Petry) several accounts of teachers being hesitant to start with a student with LDA, there are other teachers (according to Thomforde) who have the desire to teach, if presented with the necessary advice.

The key is to communicate pertinent information required for teaching and inform other practitioners who need it through one central place, which is free and easily accessible. When Thomforde created 'Another Way to Play', her rationale was in keeping with this philosophy:

I'd started another instrument adaptations website before ... [Another Way to Play] and both of them came out of just a personal interest and also having music teachers ask me questions. And I figured: 'Well, if I hear so many questions from just some music teachers that I know, there must be other music teachers out there who have similar questions and also ... people with limb differences.' (Thomforde personal interview 2022, see Thomforde 2016b).

This information would help both students and teachers gain the confidence they need to be taught and start teaching respectively. Another important point is that both the teacher and student need to be committed because adaptive methods require trial-and-error to find what is best for each individual student, as each has their own requirements for playing. Based on Thomforde's unofficial role as a consultant for adaptive teaching, there are plenty of teachers and disabled students who want to improve themselves to be better prepared and resourced for teaching and learning.

Another example of fortunate local provisions is how Dennehy and Williams were able to find the devices to play and keep their instruments stable in their own band settings, through the ingenuity of band members or family of band members without reference points (Dennehy personal interview 2021 and Williams personal interview 2019). Although solutions have been found away from school settings, this is more fortuitous than calculated. For example, if a musician with LDA is unable to find a way to learn to play an instrument, they may decide to give up music entirely because of the barriers to learning and progressing. Furthermore, if these solutions could be conveyed to organisations such as OHMI and Drake Music or to the local music education hub, a reference has been created as a potential starting point for their own music-making. Currently, these methods are being virtually lost because the accessing and sharing of information is not centralised.

In terms of funding, the organisations have received monies to execute important projects through primary funders and sponsors. The funding is paramount to assisting musicians and manufacturers in their projects. Where possible, this funding should be twinned with inhouse expertise and resources in relevant settings in order for these projects to be longterm and sustainable. The most significant disparity discovered in this investigation was the differences in funding structures between the UK and the US music and disability organisations. The UK-based OHMI and Drake Music are supported by a few primary funders, chiefly Arts Council England, as well as supplementary supporters in the form of trusts and foundations (OHMI 2022f, and Drake Music 2022e, see Meijer personal interview 2022). All four organisations do receive donations through their websites (Can-Do Musos 2017e, Drake Music 2022d, May We Help 2020d, and OHMI 2022c). May We Help does have supplementary funders (May We Help 2020e), which is more typical of the UK model. CAMC could only exist as a week-long camp because of May We Help's funding, the collaboration of the organisation's engineers, and their construction of adaptive music-making devices free of charge (May We Help 2020a and 2020h, and Petry personal interview 2018). Furthermore, these volunteer engineers needed permission from their employers to get the time off work. Those volunteers who were unable to, would construct these devices at, or through, the night (see Petry personal interview 2018).

Most in-person collaborations between disabled musicians and instrument and device manufacturers are short-lived such as the Cincinnati Adaptive Music Camp (Ibid.), as well as the Drake Music Northern Ireland Project (Samuels 2019) and the 'Music AccessAbility' hackathon in New York City (Bell et al. 2020). Although it is useful that these projects exist, they need to take place over a longer period of time, as these networks take years to establish (Woldendorp and van Gils 2012, p.236). Furthermore, these collaborations need to involve experts from a plethora of fields, who can facilitate LDA music-making. However, CAMC would be untenable in person beyond a week due to the time, effort, and monies required. For Can-Do Musos, their funding is mostly through private means such as investment and donations (Can-Do Musos 2017e, and Segal personal interview 2020). Due to Can-Do Musos being a 'casting agency' or 'referral source' (see Segal personal interview 2020) specifically for professional disabled musicians, their funding does not need to be

structured in the same way. The reason for this is because Can-Do Musos' role is focused on music industry exposure, which in turn has led to certain projects to be funded by external parties such as Channel 4's 'Yes I Can' campaign (Ibid., Can-Do Musos 2017e, and Channel 4 2016).

Another important finding from this chapter is the differences between in-person and remote collaborations. As OHMI and Drake Music are publicly funded, they are able to provide resources, personnel, and expertise in-person across the UK for various collaborations. For Can-Do Musos, they are able to provide funding for disabled musicians to travel globally to network such as at the NAMM shows (see Segal personal interview 2020 and Can-Do Musos 2017b). Alternatively, remote collaboration including the 'Yes I Can' project then allowed several members with LDA, to travel to, and work at, Abbey Road Studios (Can-Do Musos 2017e, Channel 4 2016, and Segal personal interview 2020). Adaptive Music Project, and their collaboration with May We Help, was only possible because all the students, teachers, and parents were relocated to Cincinnati in order for volunteers from May We Help to be able to collaborate for a week-long project (see Petry personal interview 2018). It is interesting that, in a hypothetical sense, if a similar collaboration occurred under the auspices of a similar organisation in the United States to OHMI or Drake Music, that organisation would be able to put funding towards projects which would get personnel, resources, and expertise to Petry and her academy in Pennsylvania.

It is not just a lack of localised teaching which can be problematic for musicians with LDA. A lack of local expertise for instrument and device making presents numerous issues. As mentioned in the previous chapter, the example of Valerie Thomforde seeking to adapt a recorder to make it playable for seven digits highlighted the fact that local practitioners were unable to help. It was not until a suitable manufacturer in the UK, Peter Worrell, was suggested to Thomforde that she was able to find a viable solution (see Thomforde personal interview 2022, Thomforde 2018b and 2020, see Worrell 2020). Local provisions have proved worthwhile, yet are limited depending on the context. Although the collaboration of May We Help and CAMC was a good local model, the project was too brief. Ideally, this collaboration would be longer and have more frequent in-person interactions. Failing this,

then it would be useful if information were extracted from these camps and relayed onto those who need it. This would allow experts and resources in other geographical locations to assist more musicians with LDA in their local areas. Another promising solution has been equipment swaps arranged by disability organisations such as: OHMI's Instrument Hire Scheme (OHMI 2022e); Drake Music's Accessible Musical Instrument Collection (Drake Music 2022a); and May We Help's Adaptive Equipment Swap (May We Help 2020a). If individualised solutions presented through these schemes could potentially be advertised to musicians with LDA, this could mean these instruments and devices could be located and transported or used as a reference point for their own individualised solution. If a virtual medium such as a video or a website were to be utilised, instrument and device makers and designers, and musicians could demonstrate how to use the equipment through visual instructions.

A further aspect of organisational support is the significance of having premises, or being in a location which allows for local collaboration, in order to conduct projects. Drake Music's headquarters has moved from an office space to a practical space (see Meijer personal interview 2022), which had the potential to enable the establishment of the Accessible Musical Instrument Collection in 2020 (Ibid. and Drake Music 2022a). The conversion to an open space can provide better provisions for musicians with LDA, instrument and device makers and designers, teachers, and researchers. If this project could be promoted successfully, it has the potential to be a leading archival library facility for adaptive musicmaking. OHMI has its head office in Birmingham (OHMI 2016a). With this localisation, OHMI is able to utilise the facilities and resources of local buildings such as the Royal Birmingham Conservatoire (the venue of the OHMI conference) and Birmingham City University (OHMI 2022d), and carry out certain objectives beyond this localisation such as the "ORP" (OHMI Research Partnership) (OHMI 2022g). CAMC utilised the resources of May We Help from their Cincinnati headquarters and connections with local practitioners and spaces such as Xavier University and Ethicon (Bonis 2016, May We Help 2020c, Memmel personal interview 2020, and Petry personal interview 2018). Finally, due to Can-Do Musos' remit, a headquarters is not strictly necessary because many of their practices occur globally. For example, co-founder Andrew Hewitt is able to operate the organisation's website from

Australia, and various members have travelled the world for promotion and networking at global events with industry partners (see Segal personal interview 2020).

Woldendorp and van Gils (2012) have recognised that there is a need for greater interconnectivity, however, creating such an extensive network would be challenging:

The musician, teacher, therapist, and constructor need to keep in touch if problems occur during the learning process ... Professional help from specific instrument builders, therapists, or doctors can be difficult to find. A lot of possibilities are available if one has good assistance. The problem is where to find this help. Even professionals, with a positive attitude regarding adaptations do not know where to find information ... Our experience is that it takes many years to build up a working network with music-related people, such as specialised doctors, a multidisciplinary team of therapists (speech therapists, physiotherapists, occupational therapists, and music therapists), orthopaedic instrument makers, music instrument builders, and music teachers. It is also important for these multidisciplinary 'music' teams to see enough musicians to gain adequate experience (p.236).

The issues of not having in-person or well-communicated projects and collaborations have been echoed by a specific example highlighted by Petry:

If you're not doing it [these processes] at a Camp, if you're not meeting every day, if you don't have the teacher right there, if you don't have the engineers right there and you're trying to do it, especially through ... a prosthetic department ... you have to make [an] appointment. You have to be there when the doctor's there ... Because it is a specialist hospital; he might be there once or twice a month. So, you're working with a private teacher ... you are renting an instrument ... and then you're going to the doctor and/or the prosthetist and it's a trip to the hospital. You're there for an hour and it's a trip back again and then you [the student] communicate to the teacher and the parent ... They're the ones trying to communicate and they're communicating imperfectly ... And you feel like half of your lesson is being spent on working with this frustrating prosthetic and the other half is actually learning music

... What you get is a parent who is paying twice as much as everybody else [to] ... get the same amount of teaching time and a teacher who may or may not get fed up of the process (Petry personal interview 2018).

This convoluted, laborious process can make music teachers quit teaching students with disabilities or never start in the first place, as they have not had sufficient training. Similarly, students may become disheartened with the constant changes required to build and develop devices needed for playing their instrument, in line with teaching which does not adhere to their standards.

To conclude, for all the organisations studied, it is evident that they are relatively small, not-for-profit organisations. With Segal's anecdote regarding the father who liked Can-Do Musos because they were not like other organisations which are, 'pity parties' (Segal personal interview 2020); none of the four organisations examined could be described as 'pity parties'. These organisations were founded and operated by creative, ambitious, pragmatic, driven, impressive arts individuals, whose goal is for the betterment of music and disability in a multitude of ways. This is supported by the personnel of these organisations, who are integral to positive change. Music has been made more inclusive and accessible for disabled musicians through various local, national, and international projects and collaborations with the musicians themselves, teachers, instrument and device makers and designers, and occupational and physical therapists. This chapter has foregrounded the fact that organisations involved in advocating for better adaptive music-making and funding structures do not have an ulterior motive of profiting or publicising these resources for personal gain. Duncan describes what he enjoyed regarding the OHMI conference:

That's what's blown me away about this thing [the 2018 OHMI conference]; it's a conference on humanity... which we so lack at the moment. It's not a conference on business ...or making money or making products even. I know there's a lot of technology involved, it's a conference on humanity and making humanity equal; giving us all a chance as human beings (Duncan personal interview 2018a).

The common goal is advocacy. Sharing information and advocacy are the cornerstones of all four organisations studied. It is therefore surprising that within the niche subject area of LDA musicality, there has only been one conference (to the best of my knowledge), which has brought together practitioners and their ideas and concepts; being the 2018 OHMI Conference (OHMI 2022d). Regarding the 2018 OHMI conference, I asked Hetherington whether he was surprised that OHMI has become an international hub for bringing these practitioners together in a single space:

In one sense it is and in one sense it isn't. In the sense that it's not surprising is that OHMI seem to be the first people ever to hold this type of conference. We just have to make ourselves known to each other (Hetherington personal interview 2018).²³

Hetherington provides the rationale for why it is 'surprising' that OHMI has become an international hub:

It takes a long time to shift public attitudes and institutional structures because they're embedded in financial structures, policies, and public opinion. In that sense, it's a marvel that anybody is here at all and that anybody knows that we exist (Ibid.).²⁴

Therefore, it is evident that there needs to be greater collaboration and communication—not only through conferences. As Hetherington states:

There's no communication and sharing between all within music and disability.

There's no central place for these people to work from. There's a lot of material around centralising music and disability information that OHMI would love to get to grips with (Ibid.).²⁵

²³ Upon review, this quotation was edited as per Hetherington's request (see Ibid.).

²⁴ Upon review, this quotation was edited as per Hetherington's request (see Ibid.).

²⁵ Upon review, this quotation was edited as per Hetherington's request (see Ibid.).

Furthermore, as the May We Help and CAMC collaboration has highlighted, the interconnection of musical and everyday adaptive devices, expertise, and methods has the potential for crossover. This chapter has provided rich material suggesting that utilising music and disability information could allow necessary conversations and collaborations to take place for the betterment of music and disability.

Conclusion

Though much needed, there is no comprehensive database of DIY musical accommodations.

Alex Lubet, disability scholar (2019, p.314)

You even saw at the OHMI conference; all of those...neat ideas that everybody was presenting, that's not something that you can just find in one place. A lot of that I'd never heard of before.

Jennifer Petry, strings teacher of students with limb differences (personal interview 2018)

This concluding chapter will draw together the main findings from the study of LDA musicality. Firstly, the empirical chapters of the media and musical representation of LDA musicality from a cultural and celebrity perspective, the grassroots, professional musicians with LDA and their approach to LDA musicality, and organisational and institutional support relating to LDA musicality will be unpacked. This will determine the main findings within LDA musicality with the throughline of advocacy at the centre of this discussion. The second section will address the second half of research question 3: 'What level of organisational and institutional support is there available for musicians with LDA and what are the potential implications of this support or lack thereof?' In order to understand the limitations of organisational support in connection with LDA musicality and LDA media and musical representation, recommendations for the future of LDA musicality will be highlighted. These proposals are presented to improve collaboration, communication, and information sharing between musicians with LDA, teachers, makers, and designers. The methods for incorporating these objectives are: displaying how music and everyday life are mutually reinforcing and adaptive by their nature, expanding to peripheral areas such as medical and therapeutic benefits through surgery, occupational therapy, physical therapy, prosthetic intervention, and even the role of non-experts; the implementation of developing a network between these practitioners with regular meetings; and the creation and maintenance of a centralised knowledge base.

What are the Main Findings within LDA Musicality?

This section will examine the main findings within the main, empirical chapters examined throughout this thesis. To begin, the media and musical LDA representation will be explored including: the overcoming and 'supercrip' narratives; the aesthetics of limb and digit absence and prosthetics as well as the incorporation of the bionic/cyborg aesthetic; the modern-day shift of LDA representation to openness and advocacy; and how genre conventions affect the musical and media representation of famous musicians with LDA. Secondly, grassroots, professional musicians with LDA and their approach to their musical instrument will be unpacked. This involves genre conventions usually being based on 'resourcefulness' and 'illusion' such as through 'sonic passing', along with LDA being advantageous for certain musical techniques, and being perceived as virtuoso by certain audiences. Furthermore, the options of musicians with LDA can be based on their own proclivities for advocacy such as choosing expensive avenues when cheaper ones exist, which will be contrasted with the use of DIY, low-cost devices being incorporated into LDA musicality. This will be followed by the importance of reference points and how these reference points take many forms. The potential of the music and disability organisations studied will then be highlighted. This will be followed by the differences in the UK-based music and disability organisations and their US counterparts in their funding structures. Then, the issues surrounding private music tuition for LDA musicality will be explored to determine how, with proven examples and reference points, teaching provisions could be improved in the future. Finally, the intervention of music education hubs within LDA musicality will be examined.

The personal, professional, and medical representation of famous musicians with LDA has an intriguing cultural context. Many overcoming and 'supercrip' stories persist in LDA musicality (see Silva and Howe 2012, p.175, and Buck 2023, n.pag). The reason these stories remain is because the narrative surrounding a musician's LDA is usually dictated by the media company the musician works with or is being interviewed by. For Rick Allen, he had an episode dedicated to his return to drumming as part of the *Fighting Back* BBC Series

(Thomas 1992). The episode included Allen's depression in hospital, his isolation during his rehabilitation on the drums, the support of his bandmates and assistive drummer Jeff Rich during a small warm-up tour, and the culmination of his return at Donington in 1986, where he 'fought back' (Ibid.). Tony lommi's story has been framed through the overcoming narrative with the *Fingers Bloody Fingers* video segment (Lima 2015). A pivotal moment in lommi's story was during his depression, he was presented with a Django Reinhardt record by his factory manager. Listening to this record gave lommi the inspiration to play the guitar again with his prosthetic fingertips (Ibid.). Even the music and disability organisation Can-Do Musos, and many of their members who are musicians with LDA were willing to be part of the 2016 Rio Paralympics 'We're The Superhumans' music video, which teamed disabled athletes with disabled musicians (Can-Do Musos 2017e, Channel 4 2016, Duncan personal interview 2018a, and Segal personal interview 2020). Overcoming and 'supercrip' stories are the easiest method to sensationalise and capture the public's attention within mainstream media. This does suggest that the general public is not going to be particularly interested in LDA musicality beyond curiosity.

The aesthetics of prosthesis and the aesthetics of limb and digit absence presents a number of representational methods. As prosthetics can move into the bionic/cyborg aesthetic, musicians with LDA may choose to use non-anatomic prosthetics. This representation provides a different lens for the overcoming and supercrip narratives because sci-fi, cyborg presentation has been celebrated within popular culture (see Braidotti 2013, p.3, and Haraway 1991, p.163-164). Viktoria Modesta became a 'bionic pop artist' inspired by Hollywood films, fetish clubs, and conceptual artists for the creation of her prosthetic designs, or on rare occasions, her partial-limb absence (Dutch Digital Agencies 2019, and Farahmand 2014). Jason Barnes' use of a prosthetic drumstick caused him to be labelled 'the world's first cyborg drummer' (Maderer 2014). The article headlines surrounding Barnes' advocacy of music-making with prosthetic technology are synonymous with the cyborg aesthetic and popular culture by their titles alone: 'Robotic Prosthesis Turns Drummer into a Three-Armed Cyborg' (Ibid.), and 'The Force is Strong: Amputee Controls Individual Prosthetic Fingers' (Ibid. 2017). The second example uses a Star Wars reference where protagonist Luke Skywalker has his hand amputated and replaced by a functioning prosthetic hand (Ibid.).

There has been a discernible shift in the media and musical representation of LDA in popular music. Decades ago, musicians with LDA would downplay the visualisation and effects of their LDA musicality, where possible. In the present day, musicians with LDA are more inclined to focus on the openness and advocacy surrounding various mental and physical aspects of LDA. Famous musicians with LDA have historically protected themselves or have been protected by other supporting musicians both visually and musically. Examples from the case studies of Rick Allen and Tony Iommi include: passing their LDA in various media settings; being isolated in order to relearn away from the public view; and the utilisation of musical prostheses such as the simplification of instrumental technique, and the creativity of bandmates on the same, or accompanying, instruments to compensate for a musician with LDA's reimagined musicianship (see Getty Images 1990, Ibid., 2010, Iommi 2012, p.3, p.23, and p.28, Longfellow 2002, Lima 2015, Lubet 2013, McIver 2014, n.pag., McNamara 1998 and 2010, Saccone 1988, p.16-22, and Thomas 1992). In a similar time period and genre of music, Jerry Garcia was able to downplay his LDA due to his partially-absent finger not affecting his personal life and musicality, in the same way as Iommi and Allen (Jackson 2000, p.9 and p.24).

It is intriguing that LDA in popular music in the last decade has shifted towards openness. Viktoria Modesta has her LDA embedded in the area of prosthetics in collaboration with fields such as art, fashion, science, and technology (Dutch Digital Agencies 2019, Hayman 2016, and Modesta 2017). These connections have become part of her brand, even perhaps her identity. Furthermore, this modern-day shift has even influenced musicians with LDA who were previously closed off such as Rick Allen to become more open in recent years regarding his LDA, predominantly the Post Traumatic Stress Disorder Allen associates with his accident (CROP Creative Media 2013, and McDermott 2022). This openness has extended to Rick Allen and Jerry Garcia (mainly through his estate) to utilise tools in the Internet Age, such as selling merchandise with a silhouette of their respective limb and digit absences to gain monies for various charities and causes personal to them (Allen 2020a and 2020b, Jerry Garcia Family 2014a and 2014b, Musictoday II 2018, see McDermott 2022).

Genre conventions can affect the media and musical representation of a musician's LDA. The segment on Iommi's history incorporates various elements from his personal background and the origins of heavy metal because Iommi's (and Black Sabbath's) musical journey underpins the lore of heavy metal as a sub-genre (Lima 2015). These factors include Iommi's upbringing in Birmingham, and the factory backdrop, which influenced Black Sabbath's sound and was responsible for Iommi's musical sound and accident directly (Ibid., McIver 2014, n.pag, and Poole 2007). Rick Allen and Def Leppard had origins in heavy metal such as their industrial hometown of Sheffield and being part of the 'New Wave of British Heavy Metal' (McIver 2014, n.pag., McNamara 1998 and 2010, and Walser 2014, p.11-12). However, Def Leppard purposely moved away from their heavy metal origins by not embracing the aesthetic of heavy metal (unlike Black Sabbath) (see Szatmary 1987, p.205, and Walser 2014, p.6). This change in style was musically-based with the hiring of a producer to facilitate their new 'sound', and adjustments across Def Leppard including the simplification of Allen's drumming technique which connected with his reimagined LDA musicality (Earl 2009, p.43-44, and Longfellow 2002). Jerry Garcia's mindset towards his LDA is befitting of Garcia's carefree attitude as a person and the laidback nature of psychedelic rock (Jackson 2000, p.9, p.86-102). For Viktoria Modesta, her LDA and prosthetics define her musically as a 'bionic pop artist'. Her most famous work, the 'Prototype' music video (Farahmand 2014), encapsulated Modesta's personal history and an attempt to push the Paralympic movement by placing the video in the advertising slot of the X Factor final (Bryant and Mawer 2016, p.87, and Channel 4 2014). However, Modesta conforms to typical pop music tropes of sexualisation and 'personal identification' (see Rojek 2011, p.3).

With the physicality of LDA musicality, the degree of aesthetic control and expression on a musical instrument is an important choice. The methods for control and expression used by musicians with LDA are connecting partially-absent limbs and digits to their instrument, bypassing by not utilising partially-absent limbs and digits, or employing alternative limbs and digits on an instrument. The choice of connecting or bypassing can be affected by the nature of LDA. Typically, musicians with fully-absent limbs and digits will bypass in order to use the dexterity (even if limited) of unconventional limbs and digits, chiefly legs and toes as a direct replacement for arms and fingers. A notable pattern is numerous armless musicians playing a variety of instruments with their feet (Harris and Gonzales 2015, Guevara 2000,

Law 2015, Schlatter 2017, and WCVE-TV 2013). Conversely, musicians with partially-absent limbs and digits may attempt to connect their affected limbs and digits to the instrument either directly or through an 'adaptive prosthetic device' as an attachment, such as a specialised guitar plectrum or cello bow (see Williams personal interview 2019, and Dennehy personal interview 2021). It is worth mentioning that these methods are not rules per se, more patterns.

The resourcefulness and illusion of LDA musicality can replicate conventional musicality through 'sonic passing'. Valerie Thomforde understands the concepts of 'resourcefulness' and 'illusion' with her seven-digit piano playing through using a device and adaptive methods (Thomforde 2017b). Jack Thomas 'sonically passes' as a two-handed drummer through his one-handed adaptive techniques and the ergonomic repositioning of the cymbals to his left side (Drumeo 2020). Besides, many armless musicians use open tunings or adapt to standard tuning when playing the guitar with their feet (Buck 2023, n.pag., Carah 2010, Dennehy personal interview 2021, Guevara 2000, Lubet 2019, p.315, and Vanderhamm 2020, p.289-290, and p.298). In some instances, having LDA can be advantageous for certain musical techniques such as barre chords for armless guitarists due to the larger surface area of big toes (Buck 2023, n.pag., Dennehy personal interview 2021, Thomforde 2018a, and Vanderhamm 2020, p.289). Additionally, Jason 'Lefty' Williams understands that his 'lack of a wrist' is perceived as beneficial for playing the guitar, despite the fact he needs an 'adapted prosthetic device' to facilitate his guitar playing (Williams personal interview 2019). Despite these techniques essentially being borne out of necessity (see Dokumaci 2023, p.5 and p.7), LDA musicality is inherently perceived as virtuoso by audiences and even inadvertently by a musician with LDA turned teacher (Vanderhamm 2020, p.290-292, and p.297, and Thomforde personal interview 2022). Therefore, practitioners who could help musicians with LDA such as teachers, makers, and designers need to appreciate that LDA musicality should be facilitated, not exist as something to be amazed by.

For grassroots, professional musicians, the genre conventions do not involve a 'star' status being maintained or a public figure being upheld. Instead, based on their own proclivities, musicians with LDA will include their methods or equipment in line with advocating for the

betterment of a field relating to music and disability. For instance, Jason Barnes and Neill Duncan chose to pursue the expensive avenue for facilitating their LDA musicality, when DIY options or adapting to an instrument may have been cheaper and potentially less timeconsuming. Barnes decided that he wanted to use EMG technology to power a prosthetic drumstick (Barnes personal interview 2019, and Maderer 2014). Barnes was willing to compromise with a two-stick prosthesis (perceiving the second stick as 'unnecessary') (Barnes personal interview 2019), in order to obtain the funding from the National Science Foundation and the expertise of Gil Weinberg at Georgia Tech (Ibid., and Maderer 2014). Barnes is an advocate for prosthetics, particularly in music-making, hence why he was willing to settle on the two-stick design (Barnes personal interview 2019). Neill Duncan, as a jazz saxophonist, would likely be aware of saxophonists playing one-handed without adaptation such as Rahsaan Roland Kirk (McKay 2013, p.14). However, due to Duncan's bandmate finding one-handed flute maker, Maarten Visser, online, Duncan decided to pursue this avenue (Duncan 2018b). Duncan needed funding from various sources in order to build the one-handed saxophone, and collaborate with Visser in person via the 2018 OHMI conference (Ibid., Duncan personal interview 2018a and 2018c). Duncan was an advocate for the mass-production of the one-handed saxophone and music and disability in general.

In contrast to the expensive routes undertaken by Duncan and Barnes, various musicians with LDA have instead (re)appropriated DIY, low-cost devices for their LDA musicality. Bill Clements' bass playing involves the use of a commercially-available device called FretWraps, which helps to control his quick fretting of the bass guitar without compromising the notes he plays (Gruv Gear 2012 and 2021). Tony Memmel decided that after trying various homemade materials to keep the plectrum on his arm, Gorilla Tape was the best solution for keeping the plectrum stable and controllable (Lubet 2019, p.315, Memmel 2013 and 2016, and Memmel personal interview 2020). In addition, George Dennehy's bandmate and a family member of Williams' bandmate were able to provide individualised devices to facilitate their LDA musicality (Dennehy personal interview 2021 and Williams personal interview 2019). It needs to be said that there are no hard and fast rules for finding musical solutions and no one is in a position to lecture how a musician with LDA should play, which facilitates the promotion of a wealth of options.

On occasion, perceived 'non-experts' have been able to create successful solutions for musicians with LDA rather than specialists. The most remarkable example of this was Andrew Tkaczyk's father being able to build a metal pad—a prosthetic bass drum pedal at thigh height (SJC Custom Drums 2019). Although it is unclear if Tkaczyk's father had any manufacturing expertise, the fact his design superseded a state-of-the-art prosthetic leg created by prosthetists at a specialist rehabilitation hospital is illuminating. The hospital was unable to translate the conventional ankle control of playing the bass drum to thigh control with no latency, whereas, Tkaczyk's father could (Ibid., and Mary Free Bed Rehabilitation Hospital 2016a, 2016b, 2016c, and 2016d). Although these interested parties are not strictly practitioners of LDA musicality, these solutions could provide vital reference points for other musicians with LDA and should be shared as far and wide as possible.

Currently, the only well-known reference points for musicians with LDA, teachers, makers, and designers are famous musicians with LDA. Barnes was aware of Allen adapting the drum kit even though he chose to find the EMG (electromyography) technology for a prosthetic drumstick instead (Barnes personal interview 2019). In addition, Jack Thomas' teacher used one-armed drummer Rick Allen as a template because Thomas was provided with an adapted drum kit through electronic drum company, Roland (Stewart 2015). This method was the starting point for Thomas, and through trial-and-error, he determined that adapting to an acoustic drum kit by repositioning the cymbals to the left-hand side and the use of one-handed adapted techniques was his preferred method (Drumeo 2020). If a one-armed drummer (or drummer with a different form of LDA) were directed to the Drumeo tutorial video demonstrating Thomas' one-handed drumming techniques, a reference point would be created.

In addition, reference points do not need to be directly related to a musician's LDA. Iommi listened to a Django Reinhardt record, which inspired him to play the guitar again (Lima 2015). Iommi did not apply Reinhardt's two-digit soloing technique (see Givan 2003, p.19-40, and Lubet 2011b, p.46-47) to his own playing. Instead, Iommi fashioned prosthetic fingertips and adapted the guitar to his individualised needs (Lima 2015, and McIver 2014, n.pag.). Furthermore, as a leading figure in heavy metal history, various able-bodied and

disabled guitarists would have used Iommi as a reference point for their own musical approaches. Reference points do not only involve the influence of another musician. Clements' aggressive one-handed bass playing technique was influenced by another stringed instrument, the Chapman Stick (Liebman 2012). The techniques adopted for the Chapman Stick involve fretting the instrument to produce notes without the need to pluck or strum the strings (Stick Enterprises 2021). Any form of unconventional instrumentation, which can be relayed to a musician with LDA may provide inspiration for how such a musician may approach their musical instrument in a reimagined way.

Reference points can provide a musician with LDA, teachers, makers, and designers with information on how a musician does not want to approach their instrument. The aim of presenting an array of reference points is to provide interested parties with a wealth of options to learn from, in order to determine the individualised needs of musicians with LDA. Although many musicians with LDA have been able to adapt to an instrument, use an adapted prosthetic device, or redesign the instrument through slight or wholesale alterations, these adaptations have been less than ideal taking years of trial-and-error. If reference points were available to learn from, the processes, materials, and collaborations could be improved in the future for musicians with LDA, teachers, makers, and designers. LDA musicality could be extended to all disabled musicality because any musical adaptation which deviates from the norm is a potential reference point. The key to this is how these adaptations are proffered. When Clements presented the benefits of FretWraps, he discussed his own bass playing but suggested that all string players of fretted instruments could utilise the device to avoid 'fret buzz' (Gruv Gear 2012). Similarly, Thomas highlights how the one-handed adapted techniques have not only benefitted him but could benefit any drummer who chooses to utilise them (Drumeo 2020).

There is a proposition for making solutions more widely available because having numerous reference points would be helpful for all practitioners within LDA musicality. Conversely, many of the musicians with LDA examined have successfully found their own methods through their own volition, posing the question: why is it necessary to have these solutions publicly available? This is because proven solutions have the potential to make equipment more effective, processes more efficient and better thought-out, costs reduced, and enable

greater collaboration and communication within LDA musicality. A particularly illuminating example is if Jason Barnes were to rebuild his original drumstick prosthetic now, the drumstick would cost less than a thousand dollars—a quarter of the four thousand dollars paid for the original (Barnes personal interview 2019). This example propounds the idea that if a musician with LDA had the necessary manufacturing information initially, chose the expensive route, and had a prosthetic device made, the associated costs and trial-and-error process could be reduced significantly, as a point of reference would exist.

The music and disability organisations studied have the infrastructure, personnel, funding, ethos, and operations to undertake a variety of local, national, and international projects and collaborations. OHMI, Drake Music, and the collaboration of May We Help and Cincinnati Adaptive Music Camp have the expertise in the form of volunteers and employees utilised within local areas. Can-Do Musos uses its workforce to facilitate the promotion and networking of disabled musicians with influential music industry personnel for future professional work. These organisations typically have a headquarters to work from. Drake Music moved from an office space to a practical space in Shoreditch (Meijer personal interview 2022), which helped with its ambition of creating the Accessible Musical Instrument Collection as an epicentre for practitioners to work from (Ibid., and Drake Music 2022a). OHMI is based in Birmingham and has successfully used its facilities and resources locally, and through the use of localised spaces such as Royal Birmingham Conservatoire, Birmingham City University, and local schools (OHMI 2022d, 2022g, and 2022h). May We Help has provided assistive devices for everyday purposes from its Cincinnati headquarters (May We Help 2020a and 2020b). For the CAMC collaboration, Xavier University and Ethicon prosthetists provided practitioners and spaces for the musicians and teachers to utilise (Bonis 2016, and May We Help 2020c). Can-Do Musos does not need a physical headquarters because its practices are global (Can-Do Musos 2017e). Co-founder, Andrew Hewitt operates Can-Do Musos' website from Australia and various members travel the world for promotion and networking at global events with industry partners (Can-Do Musos 2017b, and Segal personal interview 2020).

Regarding the finances of the organisations studied, there are differences in UK and US funding structures. The UK organisations are funded principally through primary funders

such as Arts Council England (Arts Council England 2023a, Drake Music 2022e, Meijer personal interview 2022, and OHMI 2022f). OHMI's and Drake Music's funding structures mean that personnel from these organisations are able to travel to collaborate in-person. The US organisations are typically funded through donations with supplementary funding. CAMC was only able to exist due to May We Help's funding. The building of devices, the use of May We Help's expertise, and the utilisation of localised spaces were free of charge (Bonis 2016, May We Help 2020a, 2020f, and 2020h). If OHMI or Drake Music existed and operated in the US (with the UK funding structure), personnel could be sent to Petry's academy in Pennsylvania (see Petry personal interview 2018), rather than Petry having to travel to Cincinnati. Can-Do Musos is funded through donations and by investors through Segal's connections (Can-Do Musos 2017d and 2017e, and Segal personal interview 2020). Can-Do Musos acts as a 'casting agency' and a 'referral source' (Segal personal interview 2020) for professional musicians with LDA to get music industry exposure, which means they do not need structured funding from primary funders. Nonetheless, Can-Do Musos fund their members to go to events such as NAMM by paying for their members' travel and accommodation (Ibid., and Can-Do Musos 2017b). An integral project for Can-Do Musos was the 'Yes I Can' music video (Can-Do Musos 2017e, Channel 4 2016, and Segal personal interview 2020). Many musicians with LDA were able to travel to Abbey Road Studios to record the song for Channel 4 because the television company paid for Can-Do Musos' members to work in London (Segal personal interview 2020).

Although OHMI and Drake Music have been able to work in classroom settings for individual disabled students (Drake Music 2022k, and OHMI 2022h), there is limited information for musicians with LDA seeking private tuition as well as the private teachers who could potentially help them learn. For example, Tony Memmel had to learn through informal practices such as tuition books and listening to music (see Green 2002 and Memmel personal interview 2020). Memmel was told by a local private guitar tutor that they did not believe a one-handed guitarist could be taught, which Memmel did not contest because he was of the same opinion (Memmel personal interview 2020). If Memmel or the prospective guitar tutor were aware that the guitar can be played with one hand, they would have seen a proven example and reference point, which they could both learn from as a student and

teacher respectively. Teachers can be unaware of how to help because LDA musicality is not their area of expertise (see Petry personal interview 2018).

For the teacher-student partnership of Petry and Dennehy, they both needed to be dedicated such as with the individual toe dexterity training for Dennehy's cello playing (Dennehy personal interview 2021). Furthermore, it was fortunate that Dennehy lived locally to Petry with Dennehy describing Petry as 'one-of-a-kind' (Ibid.). Most teachers and students with LDA may find that going to these lengths is overwhelming because they have no reference points. Therefore, teachers need to be willing to try adaptive methods first in order to understand how to teach musicians with LDA, using reference points as a guide for their adaptive teaching. The purpose of Thomforde creating 'Another Way to Play' was that several music teachers had approached her asking how to teach musicians with limb differences, which she felt was not isolated to a handful of teachers (Thomforde 2019, and Thomforde personal interview 2022). Despite having a limited reach, Thomforde has essentially become an unofficial consultant for music teachers seeking to adapt their teaching and incorporating adaptive equipment. Thomforde acknowledges that solutions should be individualised, which needs to be conveyed to music teachers who want to adapt (Thomforde personal interview 2022). With reference points, this individualisation and the trial-and-error process would be less daunting and make teachers and students with LDA more confident.

To supplement the investigation on music and disability organisations, the music education hub representatives discussed how their hubs provide a wealth of support for collaboration internally (Dattani personal survey 2023 and Deam personal survey 2023). A significant change in the future is the potential reduction of the number of music education hubs from 116 to 43 (Musicians' Union 2023). This curtailment could streamline processes with personnel, resources, and expertise being spread geographically across a region. Conversely, this outcome is more likely to dilute provisions for musicians with LDA meaning communication and collaboration needs to move beyond where it exists currently. It is useful that the representatives surveyed know of organisations such as OHMI and Drake Music. In particular, both Deam and Dattani were aware that OHMI is *the* organisation for LDA musicality (Dattani personal survey 2023 and Deam personal survey 2023). However,

based on the responses from the third anonymous hub representative who was unclear about LDA musicality (and potentially others who were not contacted), OHMI's and Drake Music's potential is unlikely to be well-known across the UK. This unfamiliarity may be due to having few, if any, musicians with LDA within their hub structure, thus not needing the services of an organisation like OHMI. If information on the operations of music and disability organisations could be easily conveyed to music education hubs, this would be useful for any musician with LDA within a local area.

Three Recommendations for the Future of LDA Musicality

As an important element of what I view as my advocacy in rationale and motivation for researching and writing this thesis originally, I now present and then develop three key recommendations to help fill the gaps in LDA musicality. These are:

- 1. Musicians with LDA have understood the experientiality of LDA in everyday life and music as being mutually supportive, with everyday solutions translating to creative musical solutions, and vice versa. Thus, LDA musicality has the potential to amalgamate living, adapting, and music. If this information were available to musicians with LDA, teachers, makers, and designers in a single space, solutions could be presented to practitioners from other complementary fields.
- 2. A network should be created to connect musicians with LDA, teachers, makers, and designers to facilitate greater spreading of information, resources, technique advice, prosthetics, instruments, devices, and teaching solutions for musicians with LDA. If such a network were to exist, regular meetings should be scheduled in order to facilitate greater collaboration and communication for the betterment of LDA musicality.
- 3. The overarching recommendation which could bring together and contextualise the key findings uncovered in LDA musicality, is the creation of a centralised knowledge base. In readiness for such an endeavour, future research into such a knowledge base is required. Questions which need to be considered for the existence of a centralised knowledge base are: how would this knowledge base be funded? How

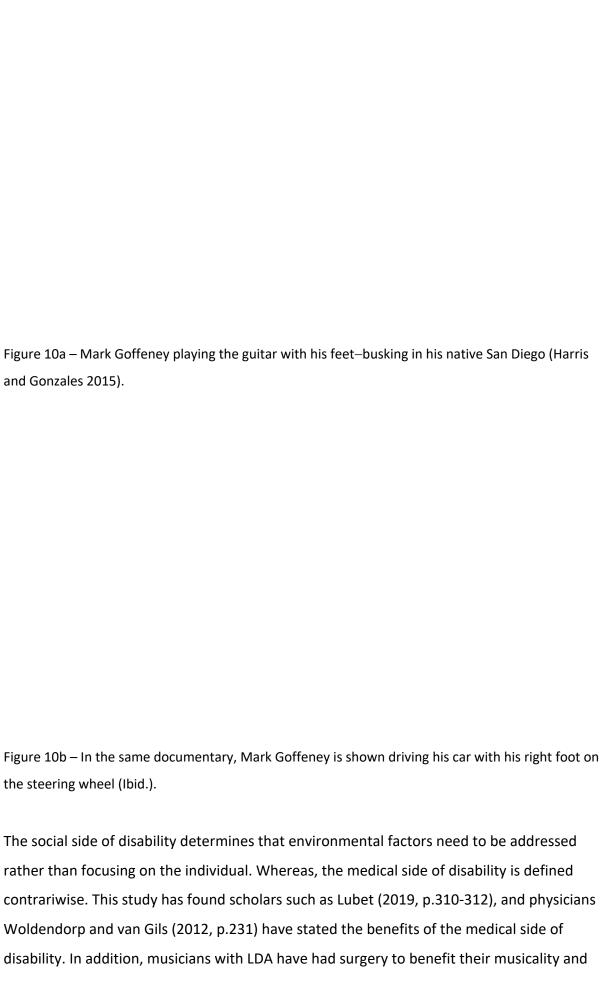
would this knowledge base be structured? How would this knowledge base be promoted to, and accessed by musicians with LDA, teachers, makers, and designers? The rationale for a centralised knowledge base is that it has been thought of, and demanded by, many beforehand, but has yet to be realised. As Lubet (2019), after all, a leading scholar of music and disability, with a keen interest in the practice of playing music also, remarks: 'Though much needed, there is no comprehensive database of DIY musical accommodations' (p.314).

Numerous musicians with LDA and organisations assisting them are advocates. This can involve musicians with LDA presenting solutions relating to their LDA or their own personal history such as: George Dennehy, an orphan with LDA being an advocate for adoption agencies and organisations assisting orphans as well as playing the guitar with his feet in public settings (Baas 2012, Dennehy personal interview 2021, and WDZ Film 2016); Jason 'Lefty' Williams sharing a video of how he ties his shoelaces (Williams 2014), formerly having a webpage of how he created his prosthetic pick device with step-by-step instructions (Lubet 2019, p.315-316), and wanting to have discussions with local prosthetic companies in order to improve the availability of prosthetics, yet the companies were unresponsive (Williams personal interview 2019); Jason Barnes seeking to improve prosthetics in general and for LDA musicality (Barnes personal interview 2019, and Maderer 2014 and 2017); and Neill Duncan seeking to mass-produce the one-handed saxophone and showcasing its possibilities during public performances and speeches (Duncan personal interview 2018a and 2018b). This extends to people from other walks of life such as Neill Duncan playing his modified saxophone to a builder with LDA in hospital, which inspired the builder to have tools modified for his impairment, days after being discharged (Duncan 2018b).

With the example of local prosthetic companies not responding to Williams' request, this highlights that advocacy does not exist by all practitioners who could assist. The reason for this is that certain practitioners have not encountered enough musicians with LDA or disabled musicians in order for their assistance to be perceived as viable (see Woldendorp and van Gils 2012, p.236). In addition, these practitioners have not been presented with proven examples of successful adaptations and devices, which could have been created locally with their expertise (see Thomforde personal interview 2022). In line with the

modern age switch in advocacy, musicians with LDA and music and disability organisations are readily willing to share their equipment, methods, and concepts with anyone who needs them, which has the potential to create greater scope for sharing local and online solutions. Thomforde did have to contact numerous practitioners in order to get the adaptations to make the recorder playable for seven digits. Although the practitioners were able to assist Thomforde regarding how to adapt the recorder, the fact that the materials were expensive and the process was going to be difficult, meant she was met with resistance. Only one maker in the UK, Peter Worrell, was able to realise Thomforde's demand for an adapted version of the recorder (Thomforde personal interview 2022, and Worrell 2020). If the information of how Worrell created this adaptation were relayed to the makers in close proximity to Thomforde, costs would potentially be reduced, and the trial-and-error process shortened with fewer materials used. Individualisation still persists because Thomforde's adaptation may not pass directly onto another musician with LDA. However, if promoted extensively, a reference point exists for musicians with LDA, teachers, makers, and designers to learn from for their own designs. Thomforde explained that when presented with more proven examples, makers and designers will understand that they could help musicians with LDA, thus reducing their resistance to assisting (Thomforde personal interview 2022).

It is clear that the integration of areas such as the mutual reinforcement of music and everyday solutions, physical therapy, occupational therapy, and medical intervention are applicable to LDA musicality. There are parallels between musicians with LDA (mostly armless musicians), using their feet to carry out everyday tasks and playing a musical instrument. This duality has been visualised in several documentaries and video segments (Callil and Moraes 2013, Guevara 2000, Harris and Gonzales 2015, Law 2015, Thomas 1992, and WDZ Film 2016). The presentation of music and everyday tasks together allows other armless people, those with differing LDA, or people assisting them to understand what is possible.



everyday lives such as Dan Caro's reconstructed thumb (Dawson 2005, p.125), Tony Meléndez's talipes (Vanderhamm 2020, p.298), and Valerie Thomforde's specific surgery to allow her to play sixths on the piano (Thomforde personal interview 2022). OHMI has recognised the importance of limb surgery having limb difference specialist consultant surgeon, Ruth Lester, as a trustee (OHMI 2022i). Furthermore, the act of playing a musical instrument can have therapeutic and rehabilitative benefits such as alleviating phantom pain, and the instrument providing wholeness, i.e. the instrument substituting a phantom partially-absent arm when playing for saxophonist Neill Duncan and bass guitarist Bill Clements (Duncan personal interview 2018a and 2018b, and Williams 2013). Jennifer Petry and Valerie Thomforde have spoken of the advantages occupational therapy and physical therapy have had for both LDA musicality and everyday, recreational activities (Petry personal interview 2018 and Thomforde personal interview 2022). Moreover, May We Help has incorporated occupational therapy and physical therapy within the services they provide (May We Help 2020b and 2020g). Physical therapists and occupational therapists are not directly involved in LDA musicality and are more likely to be concerned with everyday scenarios. If the two areas of music and everyday mutually reinforce one another, the breadth of information which can be extrapolated is greater if successful examples can be referred to.

Within the self-contained area of LDA musicality, the 2018 OHMI conference is the only global event to date (that I am aware of) which has brought together musicians with LDA, teachers, makers, and designers (OHMI 2022d). Two prominent figures in LDA musicality present at the conference, Jennifer Petry and Valerie Thomforde, have discussed issues despite the positives of this conference. Petry claims, 'You even saw at the OHMI conference; all of those...neat ideas that everybody was presenting, that's not something that you can just find in one place. A lot of that I'd never heard of before' (Petry personal interview 2018). Furthermore, Thomforde has stated that despite her visit, the 'average music teacher' would find these resources difficult to 'stumble upon' (Thomforde personal interview 2022). The reason for this lack of awareness is that OHMI is a small organisation unable to share its resources far and wide. Although this connectivity is useful, these events, and the information from them, need to exist in a centralised space where other musicians with LDA, teachers, makers, and designers can gain access. Former Drake Music CEO, Carien

Meijer, has acknowledged that even with a 'lack of signposting', there is an 'appetite for coming together' and this connectivity is a 'vital area of research' for the future (Meijer personal interview 2022).

A network of the aforementioned parties involved in LDA musicality should collaborate and provide resources in localised settings such as swap meets, instrument collections, and hire schemes. This should extend to online forums such as social media, dedicated websites, and organisational webpages shared beyond localised spaces and one-to-one encounters in order to be centralised. To broaden the scope of this proposed network, parties with a sizeable reach such as music education hubs, famous musicians with LDA and popular instrument manufacturers could contribute or have access to vital information, even if these practitioners are on the periphery of such a network. The key to a growing network is the promotion of options for musicians with LDA by sharing information on proven successful examples and reference points, which can be extrapolated for future solutions.

The best means for arranging ongoing communication and collaboration is to provide the platform for regular meetings. These gatherings would allow musicians with LDA to express their personal views as well as pay attention to opinions from other musicians with LDA, teachers, makers, and designers. This interconnectivity would provide a holistic perspective of the vital discussion points for reaching and maintaining a high level of LDA musicality facilitation. From the perspective of supporting practitioners in LDA musicality such as prosthetists, occupational therapists, physical therapists, surgeons, and non-experts, it is unlikely they would be involved in these gatherings due to having priorities elsewhere. However, minutes from these meetings could be recorded and made publicly available, if required. Alternatively, specific information could be relayed when necessary. As physicians Woldendorp and van Gils (2012) have stated, the issue of building such a community is it takes a considerable amount of time to establish these networks and would need to help many people in order to be worthwhile (p.236). Nevertheless, this networking must start somewhere. Moreover, even if professionals want to help, where to find information is a prevailing problem (Ibid.). This is why the centralisation of information for LDA musicality needs to happen.

A centralised knowledge base may have been attempted previously. However, as I am unaware of its existence, this potential oversight highlights the negatives previously discussed. I discovered through personal interviewing that: all the respondents agreed that a knowledge base would be valuable; several have previously attempted to design a knowledge base albeit on a smaller scale; and a few were prepared to collaborate for the promotion of a centralised knowledge base within their own networks including Jason Barnes, George Dennehy, and Tony Memmel (see Barnes personal interview 2019, Dennehy personal interview 2021, and Memmel personal interview 2020). Therefore, if a knowledge base were to be set up in the future, it is logical that various music and disability organisations and musicians with LDA should be ambassadors for it. Potentially with the funding structures of Drake Music and OHMI, the creation of a centralised knowledge base could be a funded, targeted project. Although laudable, the previous esoteric 'knowledge bases' which have been highlighted such as Thomforde's 'Another Way to Play' (2021) are small, relatively-isolated websites, viewed by a limited audience. Many advocates have considered the concept for a larger knowledge base such as: Valerie Thomforde and Alex Lubet having tenuous initial conversations regarding the creation of a 'Wikipedia for music adaptations' (Thomforde personal interview 2022); Stephen Hetherington seeking to add a knowledge base to OHMI's website (Hetherington personal interview 2018); and the founders of the Cincinnati Adaptive Music Camp, Jennifer Petry and Deb Amend, debating various aspects underpinning such a knowledge base (Petry personal interview 2018).²⁶

With the limited costs, resources, and access associated with LDA musicality, the notion of a 'Wikipedia for music adaptations' (see Thomforde personal interview 2022) is a possible avenue for investigation. This is because Wikipedia is an open-source website with fewer running costs than most knowledge bases of that size. Additionally, Wikipedia has been successful worldwide due to being easily accessible and promoted both through word-of-mouth and online. An integral component of Wikipedia is the categorisation and search capabilities of discovering individual pages, which are connected to similar pages on the same or associated topics (Wikipedia 2023). For a knowledge base relating to LDA

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²⁶ Upon review, Hetherington informed me that a knowledge base had moved from OHMI's funding list to potentially being on OHMI's website (see Hetherington personal interview 2018).

musicality, these pages may refer to solutions on a certain instrument, solutions for a similar type of LDA, or provide a page for prominent teachers, makers, and designers who could help create a solution for the musician with LDA. Essentially, a 'recipe book' of musical 'disability repertoires' (see Dokumaci 2023, p.27).

In order for salient information from a centralised knowledge base to be made widely accessible, further research on how to optimise its promotion is imperative. Petry proposes a hyperlink to a centralised knowledge base should be on as many related websites, and through as many corresponding networks, as possible (Petry personal interview 2018). Lubet (2019) indicates that the cooperation of distinct fields would benefit the formation of a centralised knowledge base: 'One possible collaboration would blend DIY ingenuity, the work of institutions like the Centre [for Rehabilitation and Music], and the power of medical informatics to create a free and open, well-indexed database of adaptive musical resources' (p.320). Such common arguments as cited here from both a music teacher and a scholar suggest that there is a demand for a centralised knowledge base, which needs promotion and collaboration within LDA musicality and beyond.

To conclude, it has been awe-inspiring to discover a variety of musicians with LDA, and the numerous teachers, makers, designers, prosthetists, and non-experts assisting them, possess the inventiveness to create and modify musical solutions without a reference point. Based on this fact, it begs the question: why is a centralised knowledge base necessary for LDA musicality? Although I have encountered several examples of successful LDA musicality, there must be a large number of professional musicians with LDA who have been unsuccessful in (re)gaining aesthetic control and expression on their instrument(s) of choice. This is due to a paucity of salient information regarding questions musicians with LDA might have such as: which resources/provisions/materials could be utilised to facilitate my musicality? Which maker/designer could build/modify a device/instrument for me or which teacher could teach me in order to facilitate my musicality? Can I be referred to prosthetists/occupational therapists/physical therapists/surgeons who can assist my LDA musicality? This is where the intervention of a centralised knowledge base could provide answers for these pertinent questions.

After much deliberation, the matter of improved solutions for musicians with LDA, and the advocacy which surrounds the subject area, have revealed that the creation, publication, and promotion of a centralised knowledge base would be the best course of action. This research area would: merge the knowledge of prominent professionals in relevant and complementary fields; facilitate discourse between musicians with LDA, teachers, makers, and designers in the form of regularly scheduled meetings; and provide the groundwork for widespread networking, which is vital to optimise the inner-workings of LDA musicality. Having researched the distinct area of absent limbs and digits (LDA), it is logical that the majority of the main findings extend beyond LDA to the corresponding umbrella term of 'limb differences', and the entirety of disabled musicality. Furthermore, occupational therapists, physical therapists, surgeons, prosthetists, along with those interested in virtually any form of adaptive musicality and living such as non-experts, could benefit from the relevant information presented in a centralised knowledge base if signposted correctly. Ultimately, the creation of a centralised knowledge base is, in my informed view, a necessity.

To finish, LDA musicality has been a fascinating area of study with wide-ranging implications. This has ranged from the cultural context of celebrity musicians with LDA and their musical and media representation, to the grassroots, professional musicians with LDA and their ingenious and individualised perspectives of approaching their musicality, extending to organisational and institutional support providing a wealth of assistance with small, ambitious teams and personnel willing to help musicians with LDA. This leads to the notion of expanding these concepts with a network which moves from LDA musicality, to disabled musicality, and even adaptive living. With advocacy being the focal point of this study, the creation and sustainability of a centralised knowledge base is of the utmost importance for musicians with LDA, music and disability organisations, and all practitioners who support them.

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List of Appendices

Appendix 1 – The Ethics Approval from The General Research Ethics Committee (G-REC) from the University of East Anglia.

Appendix 2 – Participant Information Sheet provided for the interviewees, followed by the Participant Information Sheet provided for the survey respondents.

Appendix 3 – Consent Forms signed and dated by all the interviewees and survey respondents.

Appendix 4 – Stephen Hetherington Interview Transcription – In person interview at the OHMI Conference in September 2018.

Appendix 5 – Neill Duncan Interview Transcription – In person interview at the OHMI Conference in September 2018.

Appendix 6 – Jennifer Petry Interview Transcription – Arranged at the OHMI Conference and conducted later as a phone interview in November 2018.

Appendix 7 – Jason Barnes Interview Transcription – Phone interview conducted in October 2019.

Appendix 8 – Jason 'Lefty' Williams Interview Transcription – Phone interview conducted in December 2019.

Appendix 9 – Tony Memmel Interview Transcription – Phone interview conducted in February 2020.

Appendix 10 – David Segal Interview Transcription – Phone interview conducted in June 2020.

Appendix 11 – George Dennehy Interview Transcription – Phone interview conducted in March 2021.

Appendix 12 – Valerie Thomforde Interview Transcription – Phone interview conducted in January 2022.

Appendix 13 – Carien Meijer Interview Transcription – Phone interview conducted in June 2022.

Appendix 14 – Yogesh Dattani Survey Responses – Email thread conducted in March 2023.

Appendix 15 – Tom Deam Survey Responses – Email thread conducted in May 2023.

Appendix 16 – Anonymous Survey Responses – Email thread conducted in June 2023.



Research and Innovation Services

University of East Anglia Norwich Research Park Norwich NR4 7TJ United Kingdom

Tel: +44 (0) 1603 591574 Email:grec@uea.ac.uk https://portal.uea.ac.uk/ren/research-integrity

Robbie McDermott School of Art, Media & America Studies UEA

Tuesday 9 January 2018

Dear Robbie,

Our reference: GREC 17-862

I am writing to you on behalf of the University of East Anglia's General Research Ethics Committee, in response to your request for ethical approval for your project 'Music and Disability: A critical investigation into a defined group of musicians with LDA (limbs and/or digits which are absent) in Popular Music'.

Having considered the information that you have provided in your correspondence ${\bf I}$ am pleased to confirm that your project has been approved on behalf of the Committee.

You should let us know if there are any significant changes to the proposal which raise any further ethical issues.

Please let us have a brief final report to confirm the research has been completed.

Yours sincerely,

pp. Polly Harrison, Secretary General Research Ethics Committee

Defelle S. M. En

Appendix 2



INFORMATION SHEET

- I have had a personal and professional interest in the field of music and disability for over seven years.
- This started with the completion of an undergraduate dissertation, which was a scoping study across most of the field of music and disability.
- From this, I have attempted to refine my research in this field, which has
 resulted in exploring the narrow, yet deep, field of musicians with limbs and/or
 digits which are absent (LDA).

I have four areas of interest:

- 1) Visual media and self-presentation.
- 2) Prosthetics, instrumentation and repertoire.
- 3) The different levels of organisational and institutional support.
- 4) The important points of discussion for better future advocacy.
- The interview will take between 30-60 minutes.
- I expect the participant to be open and honest about their experiences (good and/or bad) on these four areas of interest.
- If the participant has any issues, they have the opportunity to express their point of view to contribute to knowledge and have their voice heard.
- The interview data will be collected on two Dictaphones (a primary and a back-up) and possible video/pictures (Skype and camera if verbal permission is granted for still images of playing or as a record of our meeting).
- The participant will have an opportunity at the beginning and the end of the interview to ask any questions to the researcher about the study.
- The participant will be given transcripts for parts which will be used in the final thesis for their approval and/or to be edited.



INFORMATION SHEET

- I have had a personal and professional interest in the field of music and disability for over ten years.
- This started with the completion of an undergraduate dissertation, which was a scoping study across most of the field of music and disability.
- From this, I have attempted to refine my research in this field, which has
 resulted in exploring the narrow, yet deep, field of musicians with limbs and/or
 digits which are absent (LDA).

I have four areas of interest:

- 5) Visual media and self-presentation.
- 6) Prosthetics, instrumentation and repertoire.
- 7) The different levels of organisational and institutional support.
- 8) The important points of discussion for better future advocacy.
- The responses provided will be through an email response to a short survey.
- I expect the participant to be open and honest about their experiences (good and/or bad) where applicable.
- If the participant has any issues, they have the opportunity to express their point of view to contribute to knowledge and have their voice heard.
- The interview data will be collected and copied onto documents pertinent to the final thesis only.
- The participant will have an opportunity at the beginning and the end of the email thread to ask any questions to the researcher about the study.
- The participant will be given transcripts for parts which will be used in the final thesis for their approval and/or to be edited.

Date: 08/09/2018



CONSENT FORM

Name of Researcher(s): Robbie McDermott

Name of Primary Supervisor: Professor George McKay

Name of Secondary Supervisor: Dr Mark Rimmer

Ti	tle of Project: Music and Dis	ability: A critical in	vestigation into popular musicians	
wi	th limbs and/or digits which	are absent (LDA)		
			Please initial bo	ЭX
1.	I confirm that I have read a for the above study/project	and understood the and have had the	e Information Sheet provided to me opportunity to ask questions.	/
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.			
3.	I understand that if I do withdraw any data already collected about me it will continue to be used in the study			
4.	at or in collaboration with (AMA) at UEA in related	the School of A d ethically approv	accessed by researchers working rts, Media and American Studies red studies and at all times my accordance with data protection	
5.	I have been offered anonyr keep my participation anon more beneficial to use my r	ymous (due to put	derstand that it may be difficult to blicly available data) and it will be	V
6.	I agree to take part in this s	study.		V
The state of the s	me of Participant	8/9/18	Dr. StephenHethering	itan.
Va	me or Participant	Date	Signature	
LOBBIE MCNERNOTT		819118	Russin	
Name of Researcher		Date	Signature	

Date: 08/09/2018



Name of Researcher

CONSENT FORM

Name of Researcher(s): Robbie McDermott Name of Primary Supervisor: Professor George McKay Name of Secondary Supervisor: Dr Mark Rimmer Title of Project: Music and Disability: A critical investigation into popular musicians with limbs and/or digits which are absent (LDA) Please initial box 1. I confirm that I have read and understood the Information Sheet provided to me for the above study/project and have had the opportunity to ask questions. 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason. 3. I understand that if I do withdraw any data already collected about me it will continue to be used in the study 4. I understand that the research data may be accessed by researchers working at or in collaboration with the School of Arts, Media and American Studies (AMA) at UEA in related ethically approved studies and at all times my personal data will be kept confidential in accordance with data protection guidelines. 5. I have been offered anonymity, however, I understand that it may be difficult to keep my participation anonymous (due to publicly available data) and it will be more beneficial to use my name for the study. 6. I agree to take part in this study. Name of Participant Signature ROADLE MODERMON

Signature

Date: 08/09/2018



Name of Researcher

CONSENT FORM Name of Researcher(s): Robbie McDermott Name of Primary Supervisor: Professor George McKay Name of Secondary Supervisor: Dr Mark Rimmer Title of Project: Music and Disability: A critical investigation into popular musicians with limbs and/or digits which are absent (LDA) Please initial box 1. I confirm that I have read and understood the Information Sheet provided to me for the above study/project and have had the opportunity to ask questions. 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason. 3. I understand that if I do withdraw any data already collected about me it will continue to be used in the study 4. I understand that the research data may be accessed by researchers working at or in collaboration with the School of Arts, Media and American Studies (AMA) at UEA in related ethically approved studies and at all times my personal data will be kept confidential in accordance with data protection guidelines. 5. I have been offered anonymity, however, I understand that it may be difficult to keep my participation anonymous (due to publicly available data) and it will be more beneficial to use my name for the study. I agree to take part in this study.

Date

Signature

Date: 13/03/2019



ROBBIE MCDERMOTT

		CONSENT FO	RM	
Na	ame of Researcher(s): Robb	ie McDermott		
Na	ame of Primary Supervisor:	Professor George N	IcKay	
Na	ame of Secondary Superviso	or: Dr Mark Rimmer		
Tit	le of Project: Music and Dis	ability: A critical inve	estigation into popular musicians	
wit	th limbs and/or digits which	are absent (LDA)		
	Please tick box			
1.	I confirm that I have read and understood the Information Sheet provided to me for the above study/project and have had the opportunity to ask questions.			x
2.	. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.			x
3.	I understand that if I do withdraw any data already collected about me it will continue to be used in the study			x
4. //I understand that the research data may be accessed by researchers working at or in collaboration with the School of Arts, Media and American Studies (AMA) at UEA in related ethically approved studies and at all times my personal data will be kept confidential in accordance with data protection guidelines.				х
5.	 I have been offered anonymity, however, I understand that it may be difficult to keep my participation anonymous (due to publicly available data) and it will be more beneficial to use my name for the study. 			x
6.	I agree to take part in this s	study.		x
Jason Barnes		09/16/2019	JasonBarnes	
Name of Participant		Date	Signature	

1610912019



CONSENT FORM

Name of Researcher(s): Robbie McDermott

Name of Primary Supervisor: Professor George McKay

Name of Secondary Supervisor: Dr Mark Rimmer

Title of Project: Music and Disability: A critical investigation into popular musicians

with limbs and/or digits which are absent (LDA)

6. I agree to take part in this study.

Please tick box

1.	I confirm that I have read and understood the Information Sheet provided to me for the above study/project and have had the opportunity to ask questions.
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.
3.	I understand that if I do withdraw any data already collected about me it will continue to be used in the study
4.	//I understand that the research data may be accessed by researchers working at or in collaboration with the School of Arts, Media and American Studies (AMA) at UEA in related ethically approved studies and at all times my personal data will be kept confidential in accordance with data protection quidelines.

5. I have been offered anonymity, however, I understand that it may be difficult to keep my participation anonymous (due to publicly available data) and it will be

more beneficial to use my name for the study.

Jason Williams 11/17/19 Signature Name of Participant Date Robbie Mclemot 17/11/2019 Name of Researcher Date Signature Date: 13/03/2019



CONSENT FORM

Name of Researcher(s): Robbie McDermott

Name of Primary Supervisor: Professor George McKay

Name of Secondary Supervisor: Dr Mark Rimmer

Title of Project: Music and Disability: A critical investigation into popular musicians

with limbs and/or digits which are absent (LDA)

Please tick box

X X X

- I confirm that I have read and understood the Information Sheet provided to me for the above study/project and have had the opportunity to ask questions.
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.
- I understand that if I do withdraw any data already collected about me it will continue to be used in the study
- 4. I understand that the research data may be accessed by researchers working at or in collaboration with the School of Arts, Media and American Studies (AMA) at UEA in related ethically approved studies and at all times my personal data will be kept confidential in accordance with data protection guidelines.
- 5. I have been offered anonymity, however, I understand that it may be difficult to keep my participation anonymous (due to publicly available data) and it will be more beneficial to use my name for the study.

6. I agree to take part in this study.

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CONSENT FORM

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Appendix 4

RM: Okay. So, just to start I need you to state your name and your role, er, at OHMI?

SH: My role, er, here today or in a broader sense?

RM: In a broader sense.

SH: Okay. I'm Stephen Hetherington. Dr. Stephen Hetherington. PhD in Political Science with a thesis on cultural policy. I'm Chairman and Founder of the OHMI Trust. One-Handed Musical Instrument Trust. Do you want more?

RM: No, no. [**That's enough, is it?**] That's fantastic. [**Okay**]. So, we'll start with topic of visual media. So, in a broader sense, how important is visual media in the representation of musicians, particularly, in my case, with LDA?

SH: Okay, and when you say visual media, you're thinking of all visual media. Television, film, in particular. How far would you say?

RM: Publicity shots. [**Okay**]. Any website exposure [**Okay**]. Possibly music videos, concerts and performances?

SH: Okay. Erm, er, I think with respect to an understanding, a public understanding of, er, the existence of what is thought of, what is termed? In that pathological sense, a disability. I would say it has, er, a curiosity impact and no more. That is, er, I think that the, er, musicians, er, that, that are featured are either not featured with their disability, which is common. Might be because the photographer or the broadcaster or the whatever doesn't want to show it; er, it might be because, er, the musician has asked that it shouldn't be shown. Erm, but on the other hand, some do which is sometimes has the appearance of something voyeuristic. 'Look at this man and he's got this, that, or the other.' Er, but from a public point of view, apart from the curiosity point that: 'Look at that, look at this person whose got this disability.' Erm, I think that the, erm, the public don't really care, er, whether, it's what's happening as a response. Where what's happening... Sorry, I'm giving an extensive answer but you can always [That's okay. [Laughs]] but you can always get your knife on this stuff. [Yeah]. The, erm, where the, erm, the performance let's say; we're talking about musicians, aren't we? Popular musicians. [Yes]. Where the performance might, well, perhaps these wouldn't qualify as popular musicians but were their performances sub-standard, and that sub-standard performance is attributed to the disability, forgetting that we're all sub-standard in our own ambitions in this, that and the other. [Yeah]. But let's say that's it's, it's definitely a disinterest, except for that voyeuristic curiosity thing, the public are not interested. They don't want it to be like that. There is this thing, this sort of heartfelt, 'Little Johnny, he's doing so well, he can bang the drum.' Erm, but, er, it's not, it's not a very deep sympathy; it's a bit of a TV-like curiosity.

RM: Sure. Okay, thank you. Do you think, er, you know you're talking about in this way, do you think that your website and other visual media allow your musicians to tell a story, er, in

their own way, er, rather than have it projected onto them by, say for broadcasters doing a piece on a certain musician and they would put their own spin on things say?

SH: Oh, yeah. Erm, the interest we've had from broadcasters? within the OHMI Trust is that they've wished to feature a single person, maybe one or two but it usually comes down to one. They want a story from, er, difficulties through to success. They don't want anything that doesn't end up in success. Er, and, er, and they definitely don't want, erm, really slick professional musicians and they, where we have those discussions, they have to be quite specific and ruthless about wanting something that's either a weepy or, erm, usually about children, erm, it's that kind of approach, which we've always refused to participate in.

RM: Hmm, yeah because, erm, I've got another aesthetic of my things is the bionic/cyborg aesthetic, which brings on sort of the superhuman [**Oh gosh, yes, yes. Okay, yes**]. Aesthetic. So, what are your, I know OHMIs undifferentiated approach but, what is your feeling on the contrast of say an artificial life-like prosthesis and sort of the other type?

SH: Well, first of all, I think that falls into a category that I could, or a question that I could, generally call aesthetic. [**Yeah**]. And that applies to instruments too and if we say, as we do in the OHMI Trust, that we want undifferentiated participation. Well, let's imagine that we have a group of, of, clarinettists in an orchestra or a group of guitarists in a rock group. [**Yeah**, **sure**]. And one of those instruments looks entirely different; well, it's so context dependent. If you're in, you're one of those clarinettists and you have a different kind of instrument, then you stand out and you look odd and you'll be perceived that way. So, undifferentiated [participation] is very difficult, if not impossible because of the aesthetic of it. If you tend to the rock group, well, then instruments are often a bit bizarre anyway, intentionally and you can just be, just a bizarre instrument. It doesn't matter a damn. So, it's, it's very, very context dependent. But generally speaking, we do have a great sensitivity to the, to the, erm, aesthetic and we encourage our, the people that do come to us and we tend to prefer those instruments which try to meld in with public, and the expectations of public and other musicians, so that that aspect of it doesn't become a point of differentiation or as little as possible.

RM: So would it be beneficial if some of the, if popular musicians, just the names played some of the instruments that won your competitions or?

SH: Yes it would. It most definitely would. Erm, the, the, er, generally again, one has to generalise for this, but they are heavily protected. Getting through to them is very difficult and I know, er, from my own background which is in showbusiness, if you like. To call it that in its broadest sense but a lot of opera and ballet but, er, I've been around theatres and other things, erm, but, erm, it's often the case that, that, when you do finally get through to someone or you happen to have that occasion where you do, that's the, their resistance is, is, or far less possibly than their enthusiasm. Erm, it's getting past the agents and the managers who really don't have any interest in doing this because there's no money in it; it's a bit of a nuisance. Unless there's a new film coming up or a new book or something, you know, you just can't do it and they're deluged with this stuff. So, they edit it out heavily before they ever think even about, er, 'Should we put these things through to Joe? And see what he thinks about them?' It's very, very hard to get through but when they do and if they

speak up, yes it makes a big difference because the cameras come, the, the reporters come and your message can be packaged into that as well and then that gives, that breaks down the resistance of peoples' attitudes.

RM: Okay, great. Thank you. Erm, the few concepts I've found, erm, again through visual media of passing, reverse passing and masquerading and by passing, I mean musicians passing as able-bodied, erm, and then reverse passing is musicians who, erm, show their impairment basically as a matter of fact; you know, this is part of who I am and then they're others who masquerade their impairment where its, they're almost defined by it as it were. I just thought to your opinions to these three approaches because with OHMI it seems to be very much reverse passing i.e. normalising but never afraid because it's part of the...

SH: Okay. There's a reason for that and that it's not, we don't regard it as our business to make that decision. If we take the view that we want an instrument that allows for whatever you want to do. It's then to the musician to do with it what they like. So, we don't take, we intentionally don't go there. We just want to produce something that allows the other person, the user to decide how they want to do it. Not our business.

RM: Okay, that's good. Moving on to overcoming now, it's a narrative again with the Paralympics there's a sort of 'Superhuman' with the Paralympians, erm, and then there's the overcoming where it's, I found there's a difference between those born with LDA and those who say have an accident or an illness that where, erm, their story almost becomes a part, like a rebirth of, erm, you know, they had their life before playing music normally and then playing a different way. Erm, certainly at this conference (OHMI Conference 2018) I've found that musicians, congenital LDA musicians have found a way to tell their story, erm, possibly just through the instrument itself just saying, 'This is how I play it.' With a few, you know, specific points maybe, you know, 'This is a stand to keep own my instrument in place.' Just as a matter of fact, erm, so, erm, again I know it's not your part to say on musicians but what are your opinions on these narratives, I suppose?

SH: Erm, there's a, there's a, yeah, okay, well, again we do take this, yeah so, our position is a relatively simple one but let me just deal with some of the complexity that's out there, that you've just touched on. Erm, the difference that those who have recovered their lives, er, musical lives or found other ways to do things that they did before with the help of, of equipment, or prosthetics or instrument designs and whatever, erm, there are stories to tell which are, which fit the, erm, the traditional storytelling narrative. You have person; you develop character. There's person who has a problem, er, and it all comes through to a wonderful end where they overcome their problem. Hooray! Everyone lives happily ever after. We don't make that story; we just say: 'He wants to play the trumpet. He wants to play the violin. and? Here's one that'll do it.' And what our concern is, does that instrument give, enable them to do what it is that they want to do? Whatever that is. The other side of it, when we have someone like well, Felix Klieser (spelling?) or the Petry girls [may have to remove], erm, where they're born without arms in this case, so, that's quite a dramatic and very visual impairment/disability, whatever you call it, that certainly seems to be a problem, well, the public I have to say, on the whole, er, they want to know: 'Well, how did this all begin?' and with someone like Felix whose parents give him a French horn, stick it on the floor because he then he can push his mouth against it, you know, as a young boy. That's

the bit of the story they like. All that graft of learning this thing and studying and overcoming things like the how you get the tone of the hand and the bell; the stopping and how you do that with your embrasure and all these technicalities. No, nobody's interested, you know, it's just this: 'Oh, he was four when he did that and look at this now he's twentysomething and we got this. Forget the bit in between. We're not, it's got no interest.' And that's, that's, it's sort of understandable but, er, again we step back as much as we can, apart from personal irritations and so forth. We step back and we, we, look at, er, what we can do and er, learn from them, of course and their instruments but what we can do to enable that child or that person; that's it and then, erm, it's up to them. So, when someone like again Felix. Okay, let's take the [REDACTED] for a moment. Alright, I've named them, er, one of them is [REDACTED] and doesn't mind being named. [Okay]. And that's, er, [REDACTED]. Er, [REDACTED] likes to speak in public. She likes to talk about her condition and her approach to this has been, erm, since the first time I've met her and in several public forums?, to say: 'Being born without arms is the best thing that could have happened to me.' And it's a shock at first for people who don't, but then it explains itself because the challenges she's had to overcome in different ways, erm, have, she feels given her strengths she wouldn't have otherwise had. That it's given her a forum to speak about humanity and music and things she wouldn't have otherwise had the chance to; I mean there's a list of things that she would go through. This is a highly intelligent [person]. So, we're happy to say '[REDACTED], do you want to talk about this, in this forum because the camera is on and they will record it.' And she will say: 'Yes, I'd like to.' The other girl, who I won't name, doesn't want to talk about it so we protect her. There's nothing out there, you could, well, to the extent, to the limit that she says either we can do that, we don't do it at all and that's from OHMI's point of view, that's how we work. It's what they want and the instrument that they need.

RM: Because, erm, through my experiences as well, when I think, er, Neill Duncan yesterday with his er, conference talk, he talked about how he felt whole or complete with his saxophone, erm, so saying being told what is the best thing for you, there is a lot of people who say: 'I don't need the prosthetic intervention or anything like that.'

SH: There are. Yes. Exactly. Yes, or don't want one. [**No, no**]. Specifically, don't want one. [**Yes, very interesting**]. Yes, that's exactly like, that's exactly your point because it's a personal thing and I know the story is quite heartrending and it's a very beautiful story, the way he tells it, erm, but we don't ask him to and we don't encourage it either. It's, that's his story and I can find, I'm sure within, on the streets of Birmingham [venue of conference] now, you know, how many great stories are there like that? That would, that seem to be successful; that are highly emotional; overcoming adversity etc. etc. You know, it's a human story. So, we're just picking one of those. It's not a musical story in my view.

RM: Yeah, I agree. So, moving on to instrumental prosthesis, which is a bit of a, er, unusual, er, topic but I was going to talk to you about, er, because you have a lot of er, you know, entries into the competition. A lot of them seem to be ranging from state-of-the-art to very inexpensive things. [**Yes they do. Yeah**]. And then there's (sic) others who, er, just bypass prosthetics entirely. Again, I know you're not part of the judging panel but do you think there's any, er, preference to any one of these things? or?

SH: The judges, okay, again I'll give you a broad answer to this. The judges, erm, each come with their own personal views on these things and you can't regulate them, or generalise, you can't bring and say: 'No, it needs to be like this or like this or this.' You give them a rulebook, er, and we do debate things, er, and they come to us when we're sitting in the room and they'll say, you know: 'Stephen, I was thinking about this, you know, does that work? Does that fit within the rules? Does that work within OHMI ambitions?' And so on. But, erm, they all come with a different view and, er, some of them are quite, erm, are views we disagree with, actually. Not just about the instrument. We, actually all disagree about is the instruments. I don't think there's even been, er, a dispute that led to an argument or we couldn't resolve about which instruments have deserved to have been winners. Erm, but we do run into big issues about the approach to it about understanding the nature of disability and again, you see at some of the conference things today; I mean this, this, whole issue about, er, the social construction of disability. These are, and, and we, erm, the way in which it is described medically as these opposing conditions and all the rest that we are hearing. Quite sophisticated intellectual ideas. There's no point in suggesting that people should go around and, you know, re-understand what they, what they, made? up in their minds, er, and people they will come with a, with an angle. It should be like this. It should be like that. Very normative kind of approach to this. Er, we have to kind of roll with it a bit, er, and say: 'That's how you want it but could you do that with this instrument?' And to drag it back to the function of the, the instrument. Erm, I'm not sure that answered your question actually. Probably didn't. Try again.

RM: Probably, [**Sorry**]. Erm, it's very difficult because I was just saying about the, er, costing issue or the disparity between [**Oh yes**]. Something hugely expensive and something that's relatively cheap but I suppose, you say, I think you covered it really by way you [said].

SH: Yes, it's really just by what it does. {Yeah, yeah]. And little bit of kit; that little clip; that, you know, sometimes just a material. Somebody built this thing out of a different kind of spring steel and it's, suddenly, it does something that we think is valuable. We can see: 'Oh my goodness. Yeah, we can see how that would be used. That's valuable.' So, in a sense, we're not set out for any great sophistication and we can't set out for any particular concept of disability and I actually disagree with somebody out there today, on the stage, who said we need definitions of these things. I don't think we do at all. I don't want any definitions. It fits more with that model that we're all disabled and we're all differently disabled as we get older, you know, it's to minor or major degrees. So, it's just things that we can use that might be, you know, that help humanity to do, in this case, music. [It's just strengths and weaknesses. Isn't it?] Yeah. In everyone. Exactly, exactly and somebody else might be, we gave one of the greatest saxophonists in Britain, John Hart? He, er, learned a little bit of the one-handed saxophone for us some years ago; he's one of our patrons and, er, he played this thing, er, picked it up very quickly, erm, and then after about five minutes he went to us: 'Okay, I can see I can make this thing work. What do I do with the other hand?' So, he just thinking: 'Okay, I can play two now.' [Laughs]. And you think: 'Okay maybe we can think of something else. He can play three! I don't know.' [Laughs]. There's no telling. {No, no]. You just push this stuff out there and people make ...

RM: Fair enough. Yeah, yeah. Erm, I was just going to talk about sort of major manufacturers, music manufacturers. Are you surprised that any of them wouldn't try to, er, make even something that's got universal applications?

SH: Yes, some of them have really good kit that we want to get our hands on, you know, the Yamaha Wind Controllers, for example. Some of them are quite sophisticated and then suddenly we hear that they're not making them anymore or they've changed the ... They are pretty impenetrable, erm, the teams that do the, who are on the edge of their organisations that do a lot of research, are hard to find; hard to track down; very fast moving; people that come, people that go; policies; the funding; all those things shift quite dramatically, quickly. So, they're hard to track down. The main companies, you can think of a big list of them; very, very hard to get any interest because basically, there's no sales. Even if we find, the number of disabled people, we put a bracket around something that we now, as things stand, call 'disabled people' is huge, er, but they're all different. So, we can say within what they've called: 'the normal, even? world' you can produce a trumpet in China and you've produced 100,000 of them and there's, and so on. But if you're going to have an instrument that is for a disability, the chances are that it'll be a relatively small number that go with any particular kind of disability. You're constantly changing and manipulating and moving the weight, moving the length of this, moving the support for that; all kinds of things that go on to make it possible for that particular player. So, essentially the financial arithmetic is hopeless, er, for them. So, really it would only be done out of, erm, out of, er, well, either a marketing exercise; Advertising or an act of altruistic generosity, which is pretty hard to pull off actually. [Laughs].

RM: Yeah, fair enough. Yeah, I was going to move on to, er, specific repertoires for some of these instruments, not just these instruments but, er, things like playing with your feet so there'd be certain toe positions. [**Play like what? Sorry**]. Playing an instrument with your feet. [**Oh yes**]. So, it could be a guitar or cello. [**Yes, yes**]. Because with guitar playing, there's finger picking and certain fingers to use, thinking with feet playing you could be have certain toe positions and [**Yeah. Good**]. Do you think there would be room for some of the instruments in OHMI, and in a boarder sense, to have a repertoire build for them?

SH: Well, I, okay, we would say, er, actually, I'm going to say rather dramatically, we don't care. [**Right**]. And let me explain, let me explain that. [**Laughs**]. Because we have these little mantras, things, we say: 'undifferentiated participation in musical life', 'the potential for virtuosity' these sorts of things, right, but what we're saying is that, that, er, the, we're trying to make possible for anyone who doesn't conform to a standard physical model to be able to play music to any standard that they have talent to achieve or wish to achieve and, in that sense, whether they form a group of some strange instrument that no-one has ever heard before or play music and enjoy it or whether they join the Symphony Orchestra and absolutely square traditional instrument; very finely tuned, very fine tone, pianists? Etc. Erm, this, we just want to enable it. So, we don't ask that question. So, in some ways we'd say to get that participation, we need to go with the mainstream, erm, but that doesn't exclude us our interest in the rest. It's just that, that's, the focus because it's the mainstream.

RM: Sure. Do you think it's a similar problem when you were saying about Yamaha that there would be such a small repertoire that not enough people would pick it up?

SH: Exactly. So, it is actually one of the problems with the, the whole music therapy, technology world that one of those presentations today talking about the very short lifespan of these instruments that are produced. Well, there's one reason for it because you produce one instrument that does one set of things. Well, okay. You can play in your bathroom. What else are you going to do with it? So, it's no use and the second part of that is that, about, musical expression; this is a rather complex point for this. [That's fine]. But a lot of those instruments, those things, we move balls around; they make a noise. [Deliberate pause]. I'm going to be very disparaging for the sake of clarity and say that these are noise makers. To make it into a musical instrument, er, leaving aside, er, random, er, musical compositions, er, you need some kind of feedback and haptic control. You need to be able to say: 'I want this sound. I want this effect.' And be able to achieve it with that instrument. Well, if you're just rolling balls about, you can't do it and there's a lot of those instruments that predate OHMI, er, that are presented to the disabled community and if you go around the schools and other places where they were bought, they're not used; they're in cupboards because nobody really likes to play with them. They're not actually, the person that plays them, is not actually able to make music in the sense that they want to make music. [Yeah]. And in that sense that goes right back to the Neanderthal man. It's: I'm making this sound. I'm making this tune. I like this tune. I don't like that tune. You need control to do that. So, they don't, often, these things don't have it. [No]. The mobile phone that you wiggle around makes that. You don't have that depth of control.

RM: No. Do you, do you think they're just technical exercises almost in. [In?]. By the, er, person whose created the technology?

SH: I think in my personal view, I think they are. I think they're disguised by the language that they wrap around them. But I think they are technical exercises and, and not to say they don't have value for that. [**No, no**]. But, erm, well, perhaps I should bring that back to OHMI. For OHMI's mission, they are limited use. Having said that, we have picked up things from hacks and said: 'We think this has potential. We see it as having potential to construct it or to bring it into a playable instrument.' Er, there's a trombone slide affair, which is actually produced with or made in Hack? In Sweden, which is just a grip but by using it in certain ways with that one hand, it can produce the same effects as a trombone slide. It doesn't sound like a trombone but the sliding and the changes of pitch are achieved in a very, very similar way. So, one can build that into something that can get the tone right and the production, the note production right. So, it does have uses.

RM: Yeah, sure. Just moving on to genre. I've found a concept called the 'ethos of ableism'. [**Yeah**]. Which is, er, musical genres value, er, musicians who are fully able over those, er, who aren't. Have you found that there are any genres that have exhibited this more than others? Or [**Any genres that have what?**]. Found this is more applicable than others where the ethos is ...

SH: I think it's the wrong way round. That, erm, it's starting from intellectualising other people's worlds. [**Right**]. I think I just said that, didn't I? [**Laughs**]. [I know what you mean].

That a, I'm interested, we're interested in how people make music. [Yeah]. And how they do it and what they do it for, er, I don't really care because I can't care. I mean, it's too wide. It's too broad. It's too expressive. But I, it's a really very simple route but as soon as one intellectualises about it. As soon as one, well, this is, this is one of the problems with Government intervention and therapy, which is related. Er, in that, I say one of the problems, in that it tends to want to produce, erm, it tends to a sort of scientism. It wants to have things that are measurable as outcomes because it wants to justify the policy and finance of something else. Erm, that scientism, I think is a curse in this area because essentially, whatever might be the social; intellectual; psychological effects of performance of music on your own; with others however, are not the point. Nobody is making music because of those factors. People teaching it might be doing it for that reason. The people funding it might be doing it for those reasons but when you sit up there with your guitar and you get up on the stage and play whatever you're going to play. Who cares a f[***]. 'It's, it's amazing, this is great, I'm...' That's the point and that is an expression that we've never managed to, to explain in language. We cannot get there. Cant? Had a good go and he got pretty close but it's an inexpressible that, the value of that to human nature, it's inexpressible, it's certainly unmeasurable. So, I steer clear of all that not because it doesn't have its own values, because it's again not the OHMI mission. I'm interested in the music.

RM: Yes, okay. Fair enough, yeah. I think you've, er, there was another point but you've touched...; I was talking about the choice of instrument and how, erm, certain audiences; it's very easy to accept someone adapting to traditional instrumentation because they know the instrument itself. Whereas, the, er, because they don't understand the inner workings, well, not the inner workings, but just, they're not sure of what they've seen, I suppose, this, er, you know, I think they get an idea of how the sound's produce but they're not, er, It's hard to explain. [It's difficult to explain, I know]. Yeah, you know, there's no, erm, they can't relate to it shall I say. [Yeah]. They can't relate to what's been playing but I think we've already touched on it. So, that's fine.

SH: No, okay, well. But I understand where you're coming from. But there is this language; it's a very, very difficult language and it is difficult to explain. It's even harder when you get into a room full of politicians when you try talking about this stuff, let me tell you. [**Laughs**].

RM: Yeah. So, I'll leave the, er, ... I've got this definition of LDA. I've got a thing called congenital LDA or musicians with congenital LDA, with born, and I'm trying to find a term for, er, musicians who are not born with absent limbs... I've found LDA privation but I don't, I'm not sure of that as a term. [**Yeah**]. What are your opinions on... or is that again difficult language?

SH: Well, I don't want to avoid it, I don't want to avoid it for your sake as much as the subject. Erm, the, erm, I think the pathology argument or process is very worrying because, we are, that is now endemic, that is now how it's done, and, and, that is also wrapped up in the terminology. I must not throw criticism at you because... [**No**]. But because that would be too specific and I'm talking about a general point. [**Yeah**]. But, erm, the idea, this notion that, that disability is definable by a lack of ability of, er, or of the physical differences, erm, is a real problem because that lies at the route of this proposition of the social construction of disability. Now, I don't think, I think it will be one of, one of, the curses of academia that

one will get hold of these ideas like the social mobility and then that becomes it, but, of course, it's not; it's, it's a contributor to how we see things and, er, but so is that, well, I call it scientism and so is that negative scientism, so is that negative will to, to, erm, to, er, bracket things by absence, erm, or by addition, er, which, erm, I find is only aided by the need, actually, to put labels on things and, erm, but I can't really see how else you can describe it if you can't put a label on it. So, it's, very, very difficult. [Yeah].

(INTERRUPTION: SH: We're just doing a recorded interview, so I'll be with you in a minute. RM: It's not too much longer anyway. SH: That's fine.)

RM: Yeah, for me, it's just I have to categorise things into...

SH: That's alright. I well understand, absolutely. No, I know that's how it goes and, er, especially if you want to get through your PhD without upsetting anybody.

RM: Indeed. Yes. Er, so a lot of, erm, what I've seen; there's institutions and universities; there's instrument makers themselves; there's organisations who've collaborated with OHMI. Is it surprising that OHMI's become, certainly a national hub, but almost an international hub for these people to come together and to produce ideas and be part of a competition, I'd say?

SH: Erm, I suppose there's two parts to this one. Erm, first, there's

(INTERRUPTION. Person: Sorry to interrupt. SH: Okay, we're just doing a recording. Is that... Person: I'm going to lunch. I'll see you afterwards. RM: Yeah, no problem. Laughs).

SH: Erm, er, in one, in one sense it is and in one sense it isn't. I'm sorry, it's that problem of being academic; on one hand; on the other hand. In the sense that it, that it's, not surprising is that, for reasons which humanity should be ashamed, we seem to be the first people ever to do this and this appears to be the first conference ever. As I said earlier, on specifically this subject, not on disability but on specifically on this subject, on this approach. Okay. So, there's a lot of people around the world who are either disabled or working on some job; thinking about it, whatever. Then suddenly: 'Woah, blimey, you know. We must get in touch and we must communicate.' So, in that sense, no. We, we, just have to make ourselves known to each other. The other side of it though is because changing attitudes; changing understanding and like, erm, of the, one can see it with attitudes to, to, colour; to race; to women; to, you know. It takes a long time to shift general public attitudes. It takes a long time to shift, er, institutional, er, machines, er, and you know, this studies of institutionalism have this well-examined and well-established that, you know, it's, er, it's a, you know, the leviathan. It's very, very, difficult to steer it differently? Er, it's very difficult to change political attitudes because they're embedded in financial structures; they're embedded in policies; they're embedded in public opinion and lots of things, which we are not intending to address directly. So, er, in that sense, it's a marvel that anybody is here at all and that anybody knows that we exist. So, and I, the, the, tensions lie somewhere between the two, we should probably be shifting from one place to another place over the months and years that we operate.

RM: Just one last question. [**No, it's fine. I'm okay. It's just the noise around us**]. Sure. Erm, I've got a proposition potentially; I know it's not of interest to you but, erm, I was talking about the repertoire; things like technique advice, where there's videos of musicians saying how I play with one hand. [**Yeah**]. And they go through things step-by-step of creating maybe a prosthetic plectrum or something for playing the guitar. [**Yeah**]. And then some of the adaptions [CORRECTION: adaptations] themselves. If there was [CORRECTION: were] an online database for these things where musicians could provide links, do you think that's a, a good idea?

SH: Yes I do, I do and we've made an attempt to start it but of course, we're very small. [**Yeah**]. And we've found that, especially with the conference this year, it's blown out everything. But, erm, yes, we do have somethings on our website. Our intention was to list our winners but to, er, the availability of other things without comment, without our, you know, our imprimatur on them, so that people can make their own contacts, so that there could be more knowledge about what is actually out there and people could search for them. How that's done; how you get it; how you pro[pose]; how you structure it; how people make access to it because it can be very complicated to approach it. Erm, we haven't really mastered so, we're, in a primitive way. But erm, yes, we would like that to be done, very much and, er, we may, I mean it's probably somewhere on our funding, potential funding list to get people to do that.

RM: Yeah, okay, great. Because that's, erm, all about support networks is something else I'm finding. That just need, also, to be in one place would be very good.

SH: Oh gosh, yes. Absolutely, yes. And that's something you'll find no discrimi[nation against]. As we go [a]round this conference I think, everybody thinks that. Er, it's not just true of what we do; it's true of the whole music education [system]. The different, the 126 hubs, I think there are, music hubs. All of have got stores of musical instruments to various degrees. Erm, all different. Some of them rooms full of rubbish. Some of them running out of this but they need, but they've got loads of that. But there's no communication. There's no sharing. There's no central place. There's a lot of stuff around that subject that we would love to get to grips with. And we might. So, you know, if you're looking for a job... [Laughs]. Get on with it!

RM: I'll have to get my PhD first.[Laughs].

SH: Okay, oh, fair enough. [Laughs].

RM: No, I think I've covered everything. I'll just make sure. [Checking].

SH: Yeah, you can always come back to me. It's fine. Where, you're East Anglia, aren't you?

RM: Yes, yeah. So, if there is anything, I'll, I've got, your Exeter, aren't you?

SH: I've got an Exeter University address amongst my many email addresses?

RM: Do you mind just writing on this bit of paper.

SH: No, no, sure. That's probably the most reliable one to use.

RM: I can turn these recordings off now. So, thank you very much.

SH: Not at all.

Appendix 5

[Signing Consent Form]

ND: What's the date today?

RM: Er, the 8th.

ND: Of the?

RM: 9th.

ND: 9th, you're right. [Filling out form]. Cool.

RM: I've just got to sign [this] before we get going. [Filling out form]. That's lovely. So, it's, er, just a run through those four, er, points really. [Referring to four research questions].

ND: Yeah, yeah.

RM: So, starting with visual media, in terms of things like publicity shots and music videos and concerts, how important is, er, visual media overall in presenting yourself and your music?

ND: Presenting, ah, erm. Look, worth? my journey as a one-handed saxophone player, obviously, visual media is really important. I mean, people hear me play and go: 'Oh, I love, I like your music.' And that's been kind of a nice thing is that it is a visual thing. The onehanded thing is a visual thing. Because I play, okay, erm, people will not recognise that I have one hand by listening to it. So, obviously, they need a visual, a visual cue, to know that I'm a one-handed saxophone [player], which adds a new dimension to the music and a whole new dimension to the inspiration, somebody may be inspired by my music, which is awesome. But now, they are also inspired by the fact that I'm doing it with one hand and makes them think on a different tangent, takes, makes their thinking go in a different way, makes them start to understand it differently. And, the interesting thing is that I can do a concert, and people can be sitting 10, 10 feet away from me and come up to me after the concert and go: 'Oh, I loved that, I loved your music.' And then go: 'Hang on, you've only got one arm.' They don't see it when I'm playing. So, even with visual media, unless it's stated that I have one arm, people often don't see it because their brain does not, er, sort of, comprehend that the saxophone can be played by one hand. It's so used to seeing two hands on a saxophone that when you play it with one hand, it still sees two hands on a saxophone. It's not until I step away from the instrument, often that people will go: 'Oh my God, you've got one hand.' Which is really interesting.

RM: That is interesting, yeah, because one of my other points is, er, some musicians try to pass as able-bodied, i.e. they use publicity shots and things to hide their? I was just wandering, you've never thought about that at all, did you?

ND: No, not at all.

RM: It's just part of your story.

ND: Yeah, this is my story now and let's face it, anything to do with music, has to be honest, as far as I'm concerned. If I'm going to tell a story, I'm going to tell an honest story. That's always been my philosophy in music is the music I love the most is the honest music. Whether it's technically really bad or it's technically really good, it doesn't matter, as long as it's coming from an honest place, then it's going to have soul, it's going to, you know, have depth, it's going to swing. And so, this, this honesty, is still there. It always has been but now, there's another part to the story, yeah. And I'm definitely not going to hide that. As far as I'm concerned, it's almost a blessing because it's like: 'Okay, this is inspiring people now to listen? . I used to just inspire them on a musical level, now I'm hopefully doing it on two levels.' And that is what we're here for. To give. To inspire. It's what our job is.

RM: Yeah, er, moving on slightly a bit from visual media, with your experience with the 'Being Superhumans', the Paralympic stuff, how do you feel about, sort of, the term 'Superhumans' and things like that?

ND: Oh, you know, it's a gimmicky term. They needed a name and the whole thing with, you know, 'Superhumans' and the able band and all that sort of stuff. It's, it's, it's just a name and I mean, obviously, holds, holds, a lot more power than a normal name for a band but, you know, we always struggle with names for bands. I mean, it can take me months to find a name for a frigging band or often you go: 'Oh, that's a good name for a band. I'll have to remember that one.' You know, and it never happens for band names but this is not just a band name. It's a whole name, almost of a genre, and it's, it's like reclaiming. It's like, you know, African-Americans reclaiming, the, the N-word, you know, erm, it's kind of like: 'Yeah, that, that, that's fine. I'm okay with it.' It wasn't, I wouldn't have chosen that name, you know. It's a bit tacky but erm, don't say that. No, no, that's alright [get rid of tacky in final thesis]. But erm, you know, I just, but the thing is, yeah, they were pretty 'Superhuman', you know. These are some of the best musicians, I've played with some good musicians in my time, and these were some of the best ones I played with. And, you know, they, like, were supposedly disabled. Well, they weren't. They were very able. So, that again started me thinking about the whole concept of what is a disability and what isn't a disability and how can one be disabled and yet so brilliant.

RM: Yeah because I was thinking, I think it was in the Closing Ceremony that, I think it was Coldplay playing with a one-armed drummer. [Incorrect: it is Mat Fraser]. I was thinking it would be better, you know, it would be good for the Olympics, if it was the other way around.

ND: Yeah.

RM: If they were to play in the Olympics rather than the Paralympics but anyway, that's a whole different story. Erm, you did say in your presentation [OHMI presentation] that you referred to being very limited when you played. Can you describe the functional...

ND: Being limited?

RM: ... in your playing now.

ND: Er, it's changed my playing. It's limited. Technically, it's changed me. I mean, it's, I no longer have the acrobatics and speed I used to have but er, [interrupted]. [You're being recorded by the way]. [It's alright, it'll be cut out]. So, yeah, it is limited but I guess not to think of it as a limitation; I prefer to think of it as a change. Because, you know, like I said in my talk, it's made my playing a lot more fragile but you know, the recordings I listen to, that I like the most are the players who show their fragility: Ornett Coleman? Shows this amazing fragility in his playing and, erm, you know, Charlie Parker's Loverman, when he was so smacked out and just about to die that he could hardly move was so fragile but so beautiful and I've always loved that fragility in playing. I've never had it because I've tried, it's never been a part of me because I've always had this style that's strong. But now I don't. Now, all of a sudden, I've been forced to this fragility in my playing and I really like it. The horn is so limiting, in some ways is, but in other ways it's opened up possibilities for a new sound and a new style. And new intervals because, you know, my fingering is not the same so I'm finding new intervals. So, I'll go for an interval and it'll be a totally new interval there that I wouldn't have gone for. So, all of a sudden, I'm playing new intervals that I normally wouldn't play.

RM: Also, erm, you mentioned about being complete er, you know, the horn is your left arm almost. Because often I've found with musicians talking about, well, in their case, wholeness or they're musicians who are born without limbs. So, it is interesting how you identify as that after an accident.

ND: Er, yeah, no, I mean the funny thing is the fact that I have phantom pain, serious phantom pain, that's another thing that can make me feel whole because it still feels like I have an arm. It's there, it's sore and it's against my chest and it's paralysed and it's aching and it's horrible. But it's an arm. So, I still feel like a two-armed [player] and I get quite surprised when a kid comes up and says: 'Oh, you've got one arm, Mister.' You know, and I go: 'Oh S[...], I thought I had two.' Or I notice it. But the saxophone does that as well, you know. When I'm playing the saxophone, when I'm flying on the saxophone, when it's working, it just feels like that's my complete being right there.

RM: Sure. I know this is hypothetical but if you were born with one arm and you were playing the saxophone, because you've said about the dancing [referring to phantom fingers when playing] of your left hand, your phantom left hand, do you think it would be possible to play your [one-handed] saxophone if you didn't have that sensation?

ND: Yes. Yes. Yeah.

RM: Would it be more limiting?

ND: If I didn't have the sensation.

RM: Yeah.

ND: No, no, I don't think so.

RM: Oh, okay.

ND: That's just a, that's just a fortunate side-effect. But it wasn't until later that I started noticing that: 'Oh, every time I play the saxophone, my phantom pain disappears, you know.' Erm, even if I've got a particular, because it comes and goes, you have a day where it's chronic and then a week or two where it's there. It's always there. But then I'll have a couple of days where, for some reason, it's almost unbearable and I don't know why. But I know that even in one of the, erm, worse moments, if I play, it disappears.

RM: Sure. I'll just move on to your collaboration with Maarten [Visser]. When you were doing, well, I presume you were part of the design process?

ND: No.

RM: At all?

ND: Look. He sent me ideas and said: 'Well, I can do it this way or I can do it that way. I can do an open-hole system or a closed-hole system'. But he said: 'I think to play the closed-hole system would be difficult but it'll be in the long run means you'll be able to play everything.' **Right, okay.** Yeah, so, erm, so, I thought: 'Oh, of course, that's the one to go for.' So, there were little decisions I had to make and he would send me photographs of the keys and go: 'Does this key look like it would work for you?' So, that was all the stuff. I just had to approve things here and there. But tomorrow, oh sorry, on Monday, I'm going over with the horn and now I've got some ideas. Because I've had it for four years and now I know and now I can say to Maarten: 'This doesn't work. This would be better over here. This would be better if, it was, if it had less movement and this would be better if it was a rod and not a cable.' And so Maarten's very excited about that because now, we can collaborate now. So, the process of collaboration is about to start and through that collaboration, because of the experience I've had with the horn and because this was a prototype, erm, we can now get it pushed to that next level and hopefully push it towards the idea of getting them mass-produced for people to play saxophone.

RM: Yeah. Because I was actually going to ask: 'When did you become comfortable with it?' but the fact it's ongoing...

ND: I'm never going to become comfortable with it. **Never comfortable.** But I was never comfortable with two hands either. Yeah, you get comfortable but then you go: 'Yeah, that could have been better.' Or there's something I can't do and then the discomfort starts again because, you know, that's my next journey to, to play through those changes or to work out a technical thing you haven't got. So, it's constant. That's the beauty of a musical instrument. Nobody ever gets to the end of it. In some ways it's not the music or the achieving that makes you happy; it's the journey, you know.

RM: Because I was going actually to allude to: 'Do you think instruments could ever be, you know, adapted instruments be low-budget and mass-produced?

ND: Well, it looks like they are doing it with the recorder [School of Jewellery: Birmingham City University] with the 3D printing, which is a start, erm, whether they can eventually, erm, I would imagine as technology moves ahead, they could probably do that with the saxophone as well. But what we need is a good prototype and we haven't got it yet. We haven't got the perfect prototype yet, which is what me and Maarten look at in two days. Is pushing it towards, closer to that perfect prototype and then I'll take that home and maybe a year after I've taken that home, I'll go: 'Well, that could be good.' And then we'll do it again and then we might be getting closer and that's when we can go: 'Okay, can this be done on a 3D printer?' Because Ornett Coleman? Played a plastic saxophone forty years ago, so.

RM: Okay, brilliant. I just going to move on to genre as well. **Excellent.** There's a thing in genre about this 'ethos of ableism' so all genres of music place value on able-bodiedness and through your experience of being able-bodied and then not being able-bodied, has audience reactions, because you mentioned earlier about agents and managers [in presentation?] changed opinions as well to your playing, er, have they...?

ND: Look. To be honest, I've found that opinion towards the instrument and my music has opened people up. Yeah, managerial as well, you know. In some ways, I'm getting more work now than I was getting. I'm getting the same work that I was getting, erm, which is based on my musicality. Even though my musicality, technical ability, is forcing me to play different stylistically, the musicality's the same, you know. People know it sounds different to my ten-fingered saxophone, people will hear it and go: 'Oh, that's you. I can hear back. It's so good to hear that sound again; you're back.' It's awesome, erm, so, my musicality has remained intact and that with never go because that's who you are. And so, but now, I'm getting work and acceptance from the disabled community as well or even people that are involved with the disability community or people that are, you know. It's just opened a whole new thing because now I'm advocating for people with disabilities, so, you know, I'm here [at the OHMI conference]! **Yeah, absolutely.** You know, I wouldn't be here if I had two hands. So, my loss of my arm, as horrendous as it was, has opened up a lot of new opportunities including here, including the OHMI conference, you know, and of course, you know, the BBC, the Channel 4 thing and lots of stuff.

RM: Yeah. I was going to about, you talked about 'Whanou' [in conference speech]. Was that the word? The extended family.

ND: Whanou.

RM: Whanou.

ND: W-H-A-N-O-U. Whanou. Yeah, yeah, it's erm, yeah, it's extended family. It's just a word. But it's an important word to me because it's a good way to describe what's kind of happened to me. Erm, because I couldn't have got this done by myself, you know. Maarten, obviously; my family discovered it, you know, but also all of the people, my family – amazing support from my family; er, colleagues, you know, like I said, you know, they was so much fundraising done and people, to get here was a crowdfunding campaign, you know. I'm still

a musician; I've got four kids to raise, you know. I can't afford to fly around the world, even though I'm getting work doing, I'm still a musician; raising four kids, which is not a big living and was never going to be. So, to get this horn over here to get fixed and to do this conference through? a crowdfunding campaign and we raised \$10,000 (New Zealand currency?). That's fantastic. Yeah, and very quickly and people were like: 'This is awesome' and you know, 80% of those donations were from people I've never met before. So, you know, that's kind of 'Whanou' as well. It's that embrace, it's that, that, just, it's an awesome thing. It's a thing about humanity, which this conference is about too. It's not about making money, it's not about how can we improve our business and spread it around the world, you know. It's about, it's just about building things; it's not a destructive, it's not a, you know, it's not about using and burning and it's, it's a giving kind of thing, the whole conference. That's what's blown me away about this thing; it's a conference on humanity; on which we so lack at the moment. It's not a conference on business; it's not a conference on, you know, capitalism or making money or making products even. I know there's a lot of technology involved, it's a conference on humanity and making humanity equal; giving us all a chance as human beings. That's what it's about and, you know, people see that and then crowdfunding campaign people, you know, go: 'That's awesome. I'll support that.' And that's what I mean, we need to be helped. All of us do when we're disabled but people with disabilities possibly need it a little bit more; until they get on their feet? And I've certainly had it and that's 'Whanou'.

RM: Erm, just a few more questions. A bit more about advocacy. Could you describe your work, is it in Australia, isn't it? Is it with Parliament in Australia?

ND: What's that?

RM: Was it with Parliament in Australia? That you tried to make changes.

ND: Oh look, it's, I'm doing a lot of, starting to get a lot of advocacy work through local councils and, you know, local disability services and so, yeah, I did a speech in New South Wales Parliament and erm, I talked to Stephen (Hetherington?) who got back to me to things started up back over there. So, I mean, I'm just starting. So, I'm putting the word out there and saying: 'This is an amazing thing, you know, there is potential for people with disabilities to play music and if they can do that with music, they can do that with all the other walks of life as well.' Like my story about the builder (Conference speech reference) who got the tools made, you know, erm, it's about, you know, the potential and possibilities. I'm just trying to and er, this is inspiring people, this? And it's not even me that's inspiring people in lots of ways; it's the horn. I just go: 'Look at this. Isn't it amazing?' and people go: 'Wow, okay. Let's do that. Let's do this. Let's get the money together for that.' Let's, you know, so, that's where I at with that.

RM: Probably the last question, er, I'm thinking that creating an online database for repertoire, possibly technique advice for say for your particular instrument but it would be for everyone's particular instrument to try and get aspiring musicians, anyone who wanted to try and play the horn like you do or even just musicians? Or anyone like that.

ND: The one-handed horn?

RM: Yes, yeah, but then it would be for all these instruments just one website or database as a link for everything. So, if you're a musician and you're struggling and you don't know what to play and then you get the benefit. Would you advocate for something like that?

ND: Yeah, absolutely. It's about, but also the more you share, the better. I've got these certain sounds, some of the sounds that I played yesterday are sounds I've always had. That's just how I play. That's my style and I'm very happy to share that style with a lot of saxophone players. You know, I did the Strasberg? World Saxophone Conference and it was all classical musicians, mostly. A few jazz musicians but it was all young guys and they were all (quick finger playing noises) that sort of stuff and I was like and I walked and I heard all the stuff going on and I was like: 'Aww (impressed noise). Pfft. I'm nowhere near that, you know, I can't.' And even with two hands, I wasn't anyway, you know. Erm, but I performed and the reaction was like: 'Oh my God. How did you get that sound? How did you get that sound? What's that growl? Sound, that move? How did you play?' You know, and some of that I'm very happy to talk to players about, which I do. I say: 'Well, I do this by doing this, this and this.' And often more than not, it's not a technical thing; it's an attitude thing. And er, a heart thing as oppose to a head thing. Erm, which is hard to describe and hard to teach. It's a musicality thing but there is certain things that I'm really happy to share, you know, I have no problem with people, because I know some people took some of my ideas, my harmonic ideas that I use and I've been inspired by other people, you know, John Gilmore from the Sun-ra Orchestra? Coltrane to a degree, but Coltrane actually said: 'No, it's John Gilmore, that's done all this.' So, there's Archie Sher?, you know, Ornett Coleman? I listen to these people and I get inspired and I hear what they do and I do it, I know, and I go in my early day and I try and do exactly the same as them but I never could but what came out of it, came out of it, was a new thing. That was all mine and so, I'm really happy and you know, since then I've had players go: 'Oh, I heard you play saxophone and you were the person that inspired me to buy a saxophone and now look at me. I'm a professional player.' And stuff like that and that's awesome, you know, so, it's all about sharing work and again it's about the humanity and the language of playing a musical instrument; that's a language. Music is a language. I don't think of it as music often; I think of it as I'm telling a story; I have language, it's a sonic language, it's a tonal language and I'm telling my story, you know, erm. We've all got the right to do that and I will help anyone who wants to tell their story. As long as it's their story. Not somebody else's.

RM: Yes, yes. If I did this, it would all be, er, it's all just a database for everyone to put their stuff. So, I wouldn't impart anything myself but yeah, that's everything I wanted to cover.

ND: Good.

RM: Thank you very much.

ND: No worries.

RM: Yeah, sorry, just one more thing.

ND: Yep.

RM: Could you just, er, write your e-mail at the top there because what will happen, it will take a long time to do because I've got more interviews to do and a load of research to do, erm, is I will send you, sorry I'll turn the recording off.

Appendix 6

Commences at 00:33

JP: Hi Robbie.

RM: Hi Jennifer. Are you alright?

JP: Ha ha. Yeah.

RM: Great. Ok, erm, all ready to start? Erm, do you need me to explain anything before we start or are you okay?

JP: Erm, I actually I have two more minutes with something to do. Is it possible for me to go ahead and get out?

RM: Yeah, that's fine.

JP: Yeah. Okay. Do you want to call me back or do you want to just put it on hold?

RM: I'll, I'll put it on hold. It's fine. Thank you.

JP: Okay. Sounds good.

RM: Okay.

On hold from 01:03 to 04:28

JP: Okay. I am ready.

RM: Okay. Great, lovely.

JP: Thank you.

RM: So, just to begin the recording, erm, do you mind just stating your name and, er, your role please?

JP: Sure. My name is Jennifer Petry and I am an Orchestra Director at Veritas Academy. I also teach private students. I have a studio of about 20 students at home and about, er, 16 students, er, at another school and I also run the Adaptive Music Project, er, with a friend of mine - out of Cincinnati and we have done a number of music camps for, er, children with limb differences. Erm, I'm also a Mother of six children, five of whom have upper limb differences and, er, five of whom play musical instruments.

RM: Great, lovely. Thank you. Okay, so, erm, how the interview is going to work is I'm just going to have a list of topics and I'll move through 'em. So, I'm going to start with, er, visual

media - first topic. So, when you're doing, er, concerts and publicity photos, erm, how important is visual media for, er, representing your students?

JP: I think it's very important because otherwise, erm, you can say a thing but unless people see it, they, they don't understand it, especially if it's Different. So, back when we were in Kindergarten, the whole concept of Same/Different is something that everybody learns and it's a big learning point. And, however, that whole Same/Different concept doesn't change as we move into adulthood. I have found that when, even as adults, when somebody is confronted with something different, they generally they shut down. Even if they try to understand it, it's hard. Erm, and people will always, er, ricochet back to Same - that's their comfort level. Erm, I, that's why we have racism, that's why we have, er, all of the things you'd think adults would not have issues with. It's that whole Same/Different concept and it's no different with limb differences or disabilities of any kind really. Erm, people have a concept of what Same is or what 'normal' is and they will always go to that for their comfort level. And, erm, even my own children, their particular Same is people who were born without arms. If they see somebody who was born without legs or something's different from what they're used to within their own family, they have the same reaction as the rest of the world, you know. This is Different from me - even though I'm Different, I'm comfortable with my Difference; it's Same to me - this other thing it is Different and I cannot grasp it and therefore, it is threatening and people do see Difference as threatening. Erm, and so, a visual image shows the Different as non-threatening and as, in fact, intriguing. And so, it brings people out, helps people to understand and connects people when you can have personal interaction or if not personal interaction at least visual interaction.

RM: Yeah sure. So, erm, I remember at the OHMI Conference with your, er, concert, you were also explaining how, er, some of the devices worked in relation to certain instruments. Does that add to the visual element as well?

JP: Erm, yes. You mean to show it rather than just talked about it?

RM: Yeah but, yeah and also I mean you played a song and then you explained this is, er, for example this is a cello stand and it's for, you know, erm, holding this position. It just sort of helps, er, because you talk about the intrigue but I suppose it just further explains. So, you sort of add to the visual with the explanation as well.

JP: Yes. Well, especially in today's day and age, people are so used to the visual because of electronics. Erm, it is hard to build a visual on words with average people. Erm, at a certain point, kind of their concentration goes away. So, you can only build so many layers before, before it's gone. So, it's so much simpler to show them what it is.

RM: Sure, okay. Erm, yeah, that sort of moves me on to the language of, er, different audiences as well because, the, I've come across the, er, overcoming narrative, erm, and the Superhuman. Er, so, the overcoming is the overcoming of adversity which seems to be, er, in place for all musicians with limb differences, erm, or saying how, er, they're Superhuman for being able to become musicians. What's your opinion on, er, this, on these narratives I should say?

JP: Oh wow. Okay, so, my personal opinion is, erm, everybody has hardships to overcome and well most people do. For some people, it's coming out of poverty, for some people it's, erm, you know, even vision, you know, with, with glasses or hearing, hearing aids or even just having a hard time with hearing. I have a daughter who has, erm, hearing difficulties in one ear and it makes a difference. And it, it, erm, it, you can't really say to somebody: 'Okay, my child doesn't have arms - that's a huge difference. Your child only has hearing aids that's a pretty simple fix, you know.' Because it's not to them and everybody has their own experiences and everybody has their own resilience level. So, if you look at, for instance, children who are adopted out of difficult situations, they're dealing with a trauma that has nothing at all to do with anything anybody can see. And, in fact, they may not even realise their own issues with that trauma until they grow into adulthood but it's still very much there and it still very much hampers them and they, you know, they may not even realise that, that particular handicap. So, I, I shy away, personally as a parent, from, you know, any sort of emphasis on: 'This is so hard for you.' 'You are, look at you, you're amazing.' Because then that makes them feel different. And like I talked about the whole Same/Different thing, people just want to feel Same, they want to find their group, they want to find where they are. And when you emphasise too much: 'Wow, you're, you're a Superhuman.' Erm, then it puts them on a pedestal that makes them feel, it might make them feel temporarily strong and excited, but then when they don't feel strong, when they break down, then they are saying: 'Okay, this is not supposed to be who I am and, and people won't accept me unless I, you know, rise up to that challenge that everybody says that I rise up to.' And they're not free to be themselves and they're not free to be Same anywhere. So, within our family, we have very purposively deemphasised the whole 'Superhuman' thing. And, in fact, erm, one of the worse insults my children, erm, think that you can give is to say: 'Wow. You play the cello pretty well for someone who plays with their feet.' Then they say: 'Hey. Woah. What do you mean? That means I don't play well. No, you need to, you need to, to appreciate what I do right along with everybody else. I want to be Same with everybody else.' So, erm, I do approach things, first and foremost, as a parent and secondly, as a teacher and thirdly, as somebody who objectively researches and philosophies about these things. And erm, and I can't help but think, er, it, it would go better all-round if everybody went with a levelplaying field. And that gets me into, er, an interesting idea I have about the word 'handicap' versus the word 'disability' or, erm. When it comes to the word 'handicap', I tend to think of the game Golf or any particular family handicap parking spot or whatever. A 'handicap' simply means you're playing the game right along with everybody else but you might need a little, extra advantage. Erm, but you can still play the game – you're in the game, er, you can still park your car, you can still go shopping, you can still play the game of Golf. But a, a 'disability' is where you are disabled - you are not able to do what other people are able to do - you're not in the game. If your car is disabled, it's not running; it's on the side of the road; it is damaged. My, so, when people move from the word 'handicap' to the word 'disability', er, it really bugs me because it's not accurate. And the only reason they did it was out of a knee-jerk reaction of saying: 'Well, this word now 'handicapped' now has a, a feeling for, you know, somebody's not able to do something.' Well, yes, because that's what it is, but it's a more accurate term than 'disability'. And so, I tend to think of it as a thoughtless concept. However, I'm not really a PC person anyway, so, if somebody says 'handicapped', I just bloody, I don't care. [Laughs]. The whole concept is the same anyway and I've raised my kids to feel that way to. People struggle with trying to know what the proper term is. And so, if they're, if they are struggling at all, if they're thoughtful, they say:

'I'm not quite sure what the right term is.' I'm quick to set them at their ease. 'That's fine. Use whatever term you like. I understand what you're saying, you know.' You're, yeah.

RM: Yeah. Well, interestingly, in literature, they use the word 'impairment', erm, rather than 'handicapped'. Because they say the 'impairment' I mean, whether right or wrong, the 'impairment' is, erm, you know, the limb difference say. But they say that 'disability' is, society disables people, erm, so that's the difference they use. I don't know about the word 'impairment' and how you feel about that. Because for me that, when I think of 'impairment' I think of, you know 'visually impaired' is usually the main one that's used for things like that.

JP: Yeah. Well, I think the word 'impaired', er, implies a spectrum. [Yeah]. Because you can be 'impaired' visually, for instance, you could, you know, maybe not be able to see at all, versus being able to see where light is, versus being able to see but it's very blurry, or all the way up to: 'Oh, I have, a, a slight, you know, er, I don't, myopia whatever. I might need glasses to fix it or contacts.' Erm, and that has always been amusing to me. I don't need glasses and I never have; I've had very good vision. So, to me, anybody that wears glasses is visually impaired and I have always, kind of, felt sorry for them - felt sad. 'Oh, that's too bad. I wake up in the morning, I blink and the whole world comes into sharp focus. And you blink and you have to kind of, you know, wonder around for a while and reach for your glasses and stick them on.' And I just think of that as, as, to me, that's a hardship but nobody thinks about it that way because it's a Same hardship. Lots of people have that hardship. So, I think the word 'impairment' maybe it brings things more accurately in mind. It's nice, erm, but, but I have not thought of that word before because I, I, er, haven't, er, interacted with it in everyday life.

RM: No, sure. No, as I say 'impairment' is very much, er, the thing in literature at the moment, you know, in the academic works. But it's definitely not be used outside because, erm, yeah, I think 'disability', unfortunately, is still the given term for most of these things.

JP: Yeah, it's just inaccurate. I like the word 'impairment', it's more inaccurate. I mean, accurate.

RM: Yeah, sure. Okay, great, erm. So, I'm just going to move on now to, I've found something else, certainly through articles, erm, a thing called the bionic/cyborg aesthetic, where, erm, for example, some of the devices that, erm, you've come up with through the Camp say, for example, erm, they are a device which differs to, erm, to what they call artificial, realistic, er, limbs in function or aesthetically. So, there's some people who say: 'Oh, I really like my Terminator leg,' for example because, erm, it brings it into Popular Culture. Erm, again I just wanted your opinion on this sort of aesthetic really.

JP: I think every kid is different and every person is different and some people really care about that sort of thing. Erm, I've worked with parents before who insist that their child wear their arm at all times because they are mortified that their child is Different. And they spend a lot of energy, emotional and physical energy, and money on trying to make their kid look like everybody else. And I think, for them, it's important that the things that they receive, that the, erm, the devices that are made for connecting them to their instrument - I

think it is important that they look very nice. Erm, I, within my own family, I have a child who cares what things look like and a child who does not care at all. And, erm, however, when you're talking about music, music doesn't really exist, er, well, or fully, without an audience. And the audience is going to see what connects the device to the child and they're going to make assumptions. And so, even if the child does not care or the parent does not care, I think the audience, for the sake of the audience and the sake of the presentation of disability or handicap, erm, or impairment, to the public, I think it is important that whatever device is used, it be a polished one and a beautiful one. Which is why our, our, very first cellist(?) in was made out of metal, like these square long metal rod type things. And it was not only ugly as all get [up], it looked like the bare bones of some high rise building before anything had been, like walls had been attached or anything. It was also dangerous. [Laughs]. I once cut myself on it and the cut took about a month to heal and it was nasty and all I did was, you know, brush my foot up against it. Er it, but the final product, which we didn't see actually because we have, we took the transportational(?) stand over there, but our final product is made of walnut and it is beautifully sanded and polished and it's shaped and it, the girls really appreciate that. I have to carry them and they're heavy. So, I don't appreciate them as much. [Laughs]. Erm, but they do. And, erm, they like a little bit of colour like when they put the, the bow holder on their bows and I will attach it with, er, pink tape or whatever. Er, I thought at first it was kind of garish but Inga really likes that, you know. She says: 'Oh, this is my colour. This is my statement, you know.' Okay. Erm, yeah, the rods – silver versus gold. The golden ones are more expensive but we asked for them anyway, you know, that sort of thing. Erm, and I know kids who like their initials, er, etched into the device or whatever. It just makes it special for them. And when it comes to the audience, because of that whole Same/Different concept, you want the audience, if they see the Different, they wanting to feel the Same. And when you make something beautiful, they're going to feel closer to that child or to that product, erm, and I think that is important. I think that definitely needs to be taken into consideration.

RM: Okay, great. Thank you. Erm, so, yeah, I was just going to move on to the, the process of, er, getting these devices built. Because, erm, especially with Camp I was looking into was, er, you worked with the, er, child in terms of, you know, how they're going to play the instrument, er, [prosthetics] devices they may need. Erm, so, how long roughly would that process take or could it vary?

JP: It takes years. Honestly, it takes a lifetime. Because, erm, as a child grows their, erm, their needs might change because they, erm, become more involved, er, with whatever they're doing they might need a more advanced technique. We try to take that into account right from the start, but the fact of the matter is, erm, when we were very first starting out with the bow holders, I knew my children would need to be able to use a spiccato later on in life, but they couldn't do it then. So, they couldn't, they couldn't show the engineers what they needed to do. I could show them with my hand but it's not quite the same. And we built in some concepts for helping make that happen right from the start, but it didn't really get refined until they could do the spiccato, erm, because they then knew what they truly needed. Er, the other thing is usually the prototype is not helpful. Er, Often, it is, it is frustrating and a waste of time and that, those are just the facts. Erm, it's why we have our Camp - to go through that prototype process in a condensed manner. Because if you are, er, if you're not doing it at a Camp, if you're not meeting every day, if you don't have the

teacher right there, if you don't have the engineers right there and you're trying to do it, especially through like a hospital like trainers that has a prosthetic department but you have to make appointment, you have to be there when the doctor's there, then the doctor's not there every day because it is a specialist hospital, he might be there once or twice a month. So, you're working with a private teacher that you're paying, you are renting an instrument that you're paying for and then you're going to the doctor and/or the prosthetist and it's a trip to the hospital, you're there for an hour and it's a trip back again and then you communicate to the teacher and the parent, who may or may not be a musician, who may or may not be very, er, with it when it comes to the prosthetic making. Erm, they're the ones trying to communicate and they're communicating imperfectly. And it takes years sometimes and, and you feel like half of your lesson is being spent on working with this frustrating prosthetic and the other half is actually learning music. And so, what you get is a parent who is paying twice as much as everybody else is in order to be, get, get the same amount of teaching time. And a teacher who may or may not get fed up of the process, erm; really depends on how much they're on board - many teachers won't even start, in fact most teachers will not start a, a child with a limb difference. They just say, right from the start: 'I'm not going to do that. That's not my area of expertise. That's not what I went to school for. That's not what I've done for years and years. You need to go find somebody who knows what they're doing.' Well, you know, somebody who knows what they're doing is so rare. So, erm, I would say that building and developing these devices, er, that start out, some of those kids will quit, erm, but those who do not quit, it is, it is a lifetime process. I know exactly what my children need when it comes to devices. I know what they need from the musical side of things and I'm pretty well-versed with the OT side because my family is doctor, is full of doctors. My, erm, sister's an OT and I will get free advice from them any time I want - my sister will come work with my children any time I want. But, erm, and we have this engineering group that we've been working with, but every year, we come up with a new iteration, a new version, a new tweak that makes it easier and better and they're happy to work with us, we're happy to work with them. But for us, this is why we started the Camp. The only reason we got this far is because a) I refused to give up. Erm, these are my children and a mother will do anything for her children and I'm a musician. It was not an option for me, for my children not to be raised musically. So, erm, and I'm a string player, so, for me, I really wanted to see them play strings. Erm, although, I mean, one of my kids plays French Horn; another kid plays piano, it's not, it's not like, I'm, I said strings or bust. However, I knew how to do the strings thing and I didn't know, there was no OHMI over here to modify the instruments, you know. I knew they couldn't play a wind instrument without fingers. So, although I've since found you can the French Horn with your feet and you can play the trumpet with your feet but, erm, you know, that took a while. So, I would say the process takes a lifetime but I would say the initial process probably takes a year or two to get a real, honest to goodness working prosthetic. I don't know anybody that was just able to get what they needed right from the start and that is why the camp began. To try to make that process less painful. I would say of all the students I've seen, there's only one that, actually two perhaps, although I didn't do the follow-through with the second one, where, they were starting out with a prosthetic though, so I'm not sure this qualifies, but they started out with a prosthetic thinking they needed all this stuff, came to camp and said: 'Oh, I'm a mess, you know. I'm ready to quit. This is my last-ditch effort.' And I just took everything away and said: 'Look, your hand, even though it doesn't look like everybody else's, it can do this.' And then that's all they needed. And from there, they went on and

they're in regular youth orchestra, they don't have any devices at all but their hand does what they need it to do. Erm, and so, sometimes it's that too. Sometimes it's, you work and work and work with a prosthetic and then you realise: 'Hey, I don't even need this.' Erm, and that happened to another person to - I just video-skyped them, to work with them. Erm, but the issue with them was not their prosthetic at all, it was their teacher. Their teacher was teaching them incorrectly or not seeing something that I saw. And so, I was able within half an hour – the teacher was supposed to be there and did not manage to get there in time; they got stuck in traffic or whatever, and the student said: 'Well, please just work with me. I'm desperate. I'm ready to quit.' This was an adult person. And I said: 'Okay, erm. Well, here's what I would say.' And, without casting any aspersions on the teacher; erm, I was very careful about that, I just pointed out a few things they could be doing differently. And she tried it and immediately everything worked and she said: 'Woah. I, I can do this now.' 'I know. Okay, great.' After that, she didn't need me. She just, really what she needed was a teacher who, er, knew what they were doing. And that, I don't know if this is going to be part of your question but, erm, at some point, I will say one of the biggest struggles for a student with a limb difference is finding a well-qualified teacher. And by that I don't mean somebody qualified to work with limb differences, I mean somebody who actually just teaches well. Because learning a stringed instrument is, er, it's hard. It's, it's really hard for anybody and it takes a lot of teeny-tiny baby steps and I'm convinced if anybody knew what it took ahead of time, they wouldn't do it, unless they were a very special kind of person. But, erm, if you, if a teacher knows what they're doing, they can make the whole process enjoyable and, erm, and, and with minimum, minimal frustration but you really have to know what you're doing. You have to the angle in sight, you have to know what posture needs to be set up and you need to set it up well and then insist on it because it's not a natural position for most kids to be in. And when you let a child do what they want to do, which is have terrible posture, because you feel sorry for them. And this goes back to the Superhuman question, you know. 'Oh wow, you're putting all this effort in. I can't imagine asking you to do more. So, I'm not going to insist that you play with your fingers angled this way.' Or, you know, whatever it might be. And what you're doing is you're just creating an implosion waiting to happen. And I will say, erm, of the many kids I have seen playing an instrument, a stringed instrument with a device of some kind, half the time, most of the time maybe even, the issue is not with the prosthetic device. The issue is with the other hand, that's just fine, that hasn't been trained well because all the focus has been on the prosthetic.

RM: Sure, yeah, yeah, yeah. Erm, so, I'll move onto, er, I was going to talk about repertoire as well. So, erm, for certain, for example, you have finger positions for certain, er, notes played. Erm, so, could this, or has this, been adapted for say playing with, with your feet or is there any sort of technique advice that has been used as, er, alternative methods at all?

JP: Um. Good question. Really good question. Okay, so, erm, the, actually the piece my daughter played, erm, with the Orchestra, the Vivaldi, has a section in it that requires, really to do it well, you have to have this huge stretch in the, in the hand. And the feet just don't stretch the, you know, fingers are long, and feet, toes are not. And so, her stretch is not quite the same. And, erm, rather than, er, she's also a kid. [**Laughs**]. And, and, erm, so, rather than frustrate her, er, her teacher did modify the notes to a portion of the song. Erm, my opinion on that, I decided to, because she has another teacher now, I took her to a

certain point and then because of, because of the fact that we're a mother-daughter team and because I felt like she needed to grow through another person. Erm, she goes to lessons but I'm there the whole time with her and, erm, the teacher gets my input and, erm, on any adaptive stuff and he just said: 'You know what. I'm going to make this easier for you, we're going to do it this way. You're not going to have to find that note that's like way out there, that you have to stretch for.' Which she could've kind of hopped to but it sounds a little sloppy and this way, it just lowered the stress level. That was great. She's also preparing for an audition tomorrow for PMEA, which is Pennsylvania Music Educators' Association, it's, er, it's, it's, you know, the honour that everybody strives for, just to be included in this orchestra. And then, from there, it's at the District, Regional and All-State level and once she hits All-States, that's considered, you're considered then one of the best youth musicians in the entire state of Pennsylvania, which is no small thing because Pennsylvania is really large. Erm, she is auditioning on a piece that is considered All-State level and, erm, and it has a section in it that has double stops. And, erm, at first, she just refused to do them. And that also is a whole different, er, topic if you want to talk about the, the stubbornness of a child with limb differences and how that develops, erm, we can talk about that. Because it's a really big psychological barrier to learning, erm, and I found it over and over and over again in the students I've worked with. Erm, and I found it very interesting because I had thought that it only existed in children with traumatic backgrounds and yet I had been seeing this and I realised, you know, being born without a limb is, in essence, it is a trauma; that a child has to deal with in a certain way and it, it looks like trauma and it can, anyway, but that's a whole different topic. So, she, so, she said: 'I can't play that. I'm not going to play that.' And the teacher said: 'Okay, just play the top part.' And I gritting my teeth. [Laughs]. Because I know that she can play that. But I went along with her teacher; that's why I take her to somebody else, so that, you know, there's a, there's a report that we can have that's different. And, erm, he, he did this with her. He had her playing that top line and the top line only for months, and because it takes months to prepare this piece. And then a couple of weeks ago, he said: 'Oh, oh let's see about that, those double stops. Let's work 'em a little bit.' And she came home and, and she practised once again the top line and I said: 'Ah daughter. Your teacher told you to do, these, these double stops.' And she said: 'Yeah, but I'm not going to. I can't play them.' And I was fortunately too busy to engage her in this; I had to do something else and I just left it. And then the next week, he once again said: 'Oh double stops.' and he said: 'Show them to me.' And she, although she had not practised them at all, yet what she had learnt the week before had still stuck with her and she played them and she said: 'Oh, I, I did it. I can't believe I did it.' And he said: 'Yeah, I thought you could.' And then she went home and she practised that like crazy. This is mind you two weeks before the audition. Crazy to take the most difficult technique and just, just barely be starting it two weeks before an audition. But now, she went ahead and she recorded it with me a couple of days ago, her audition is tomorrow, and she plays it perfectly. And she still surprises herself every time she plays it, she gets that thrill of: 'I can't believe I did that.' And, erm, so, yes, sometimes it needs to be modified, erm, and Valerie Peters is a really good example. She modifies her piano, er, notes to work for her. But I think also, it's a good idea to still, even if you say: 'I can't play this part.' I think what the attitude should be is: 'I'm going to play it this modified way. I'm going to modify it for me or the teacher modifies it for the student but I'm going to keep chipping away at whatever that technique is that I think I can't do right now because I might be able to do it in the future. I'm unique and nobody can really tell me where my barriers are, including myself. Nobody knows where my barriers are

because I am different and this is a good kind of different. Let's keep challenging myself, while at the same time making sure I have a back-up plan that's completely playable.' So, that's my take on modifying, er, the notes themselves.

RM: Okay, great. Thank you. Erm, I'm just going to, er, move back to a point about the prosthetics themselves again. Erm, actually I'll talk about when you begin with the students. If you have a prototype, er, say from the year before and a new student comes in and they have similar limb differences, can you automatically say: 'Well, we tried this with this student last year and these things worked. Erm, you know, do you fancy giving it a go, just as a starting point?' Or do you try and, just individualise it for every student that comes in?

JP: Erm, definitely starting point. There's no point reinventing the wheel. However, I will tell you, I have never ever had one prosthetic transfer 100 per cent to the second child. Now, I don't, you know, I don't have that much experience. I have a lot of experience but I don't have enough experience that I'm going to say that's 100 per cent going to be the case. But I can tell you, my two daughters both play with their feet and they have different bow holders. They have the same concept but they're different angles, different lengths, heights, different, er, er, lengths. And the reason is they have slightly different feet and they have slightly different ways of playing. And I, again with the stubborn, erm, I have a daughter who plays more loosely and because of that, erm, is able to do more. And I have a daughter who plays with a lot more tension and work it as much as I might, erm, with a, with a typical, a, a neurologically typical kid, I can get them to relax. Er, it might take years but I can make it happen as a teacher working hard enough. But when you're dealing with a kid who comes from trauma, a troubled background and my children do; it's not only the limb difference but also adoption and, er, abandonment and that sort of thing. Erm, there's a stubborn streak that is, er, anti, erm, er, there's a word I'm thinking of, but I'll just use more, more of a simple word, it's anti-helpful. It is. It is a stubborn streak that says: 'I'm not going to do it your way because I didn't think of it first and I don't trust you. And I don't trust anybody but myself to know my, what my own adaptation limits are. And I feel tight and I feel tense. I'm going to make this happen. I want to play this piece and I'm going to do it by physically manhandling this instrument.' And that's how most kids think if they're aggressive or, erm, but usually you can get a kid to kind of let go and. But a kid with a traumatic background, that's a lot harder to do. And when I've taught kids with all their fingers and toes, who come from a trauma background, and they're tense and tight, there are times when I, it's, it's years in the working and it gets better and better and better but there's still that tension left over that we're constantly working on. And I would say, so that's what, that's what, er, what one of my kids has, that, that same tension that is much more than just a physical issue. And so, because of that, they need a different device for how to approach their instrument and I think that definitely needs to be taken into account. We need to look at more than just the physical needs of our students.

RM: Right, yeah. That's good because, erm, these differences that you're talking about. Because I was going to move on to, do you think any of these prosthetics could ever be, erm, you know, low-cost and mass-produced but if they're individual differences I guess they're never ever going to be the case really.

JP: I will say that, erm, there, there's Adrian Anantawan from Canada. [Yeah]. He has a little, erm, he has a device that he, I don't know who came up with this idea, but it is sold. You can buy it on the Internet and, erm, I know people who have done that. And, erm, it has helped them get up and get started, which is great. Erm, it may even be a solution for more than just him. It, it may be a perfect solution for a couple of people. Erm, However, I know that some of the people I saw using it, I thought it could have been tweaked a little bit more. Because I'm, I'm very into, with, with a stringed instrument, the vibration of the instrument itself gives feedback and it's a, it's a, a really important sensory aspect of playing that you feel what you're connecting to. And when you put a prosthetic device in between your hand and the instrument or your foot and the instrument or your body and the instrument, you are disconnecting yourself from that instrument in a way that makes your playing experience less than somebody who's connecting with that instrument would have, no matter how that connection is. So, my, my emphasis is to always try to connect skin to instrument as much as possible. And there was one particular student I taught who had a hand very similar to Adrian's. And what we did, it meant that the bow, the, the arm length was a little shorter but I thought it was worth it in order for her to put her little stub on the bow itself. And we put a hole in the device, so that part of her hand could be touching the wood of the bow, so that she could feel that connection, that sensory input. And erm, I felt like that was a really good move. I liked what it did. I liked the more control she could have. And not only that, and this is a very interesting, er, side-aspect of what we do, it was good for her, erm, it was good for her the, the development of that hand. She was able to find something she could do with it, to move it, to manipulate something. And her parents were part of that. So, she was able to then, she, er, kind of, transferred to that to the rest of her life. And she was more willing to use that hand to do things because she was using it on her instrument. And I've heard that a couple of different times, parents have come back to me and said: 'I don't even care about the music anymore. What this is doing to my child's, erm, occupational therapy is wonderful.' So, I thought: 'Ah, okay.' I've seen that in my own kids as well but, erm, so, that, that's nice.

RM: Yeah, yeah, definitely, yeah. Okay, great. Erm, I'm going to move, er, onto genre now. Erm, in particular, er, obviously the field of classical music is what you deal in mostly. So, I was going to talk about, so, you take it from school level but how is, er, the perception in, er, traditional orchestras because I know, er, there's, you know, an emphasis on perfectionism and even having someone, er, you know, one of the instruments that's sitting differently, erm, can throw that completely out. So, erm, how has your dealings with those been really?

JP: Erm, I have children and so, people are pretty much willing to do anything for a child. Erm, so I can't speak to the adult aspect. I will tell you the auditions my children take are usually blind and I find a great comfort in that. That the judges' backs are turned. I bring the, the cello in as quietly as I can so that they cannot tell. And usually, the judges do not know ahead of time that they're going to be listening to somebody different. They only know it after the fact. Usually, they are shocked, erm, and intrigued and, erm, because they judged fairly and my child still got into the orchestra and they are thrilled. And erm, so usually when that happens, I mean the judges are hired to make a choice based on sound and only sound. And erm, if my child got in based on that without knowing ahead of time, nobody, I mean there's never even been a thought of: 'Oh this, erm, you know, this shouldn't be. This child

doesn't belong here.' So, usually once they realise: 'Oh, this child belongs here.' Then they, erm, they will, they will be very willing to do whatever needs to be done to, to have that child participate. [Sure, great]. And even if everything can be, I have found that all of the orchestras we have been to, and that includes Honours Orchestras and erm, Festival Orchestras, er, Regular Orchestras, Youth Orchestras, not only, oh and, and Camps like Peabody Chamber Music Camp is one and that's, that is, that is, a, a hardcore, you know, you have to audition just to get into the Camp and they only want a certain level, erm, they will, erm, er, they will themselves, er, ask, they'll say: 'Okay, train us in how to move this, this instrument safely and we will assign somebody and your travel will be taken care of.' And er, that's, that's, that's thin-on? experience, which is, is great. It, I'm not sure what my experience would be if I went also, an Orchestra Director, sending other students to the same things, making sure that, you know, everything's well-prepared and I have a good reputation but, you know, I can only know what I know.

RM: No sure. That's fine. Yeah, great. Okay, erm, I'm just going to move on to, er, the collaborations with the other organisations, so, er, especially with the, er, Adaptive Music Camp, erm, I know about May We Help and few of the other organisations. Could you, er, just explain how they help at all?

(Pause in recording 45:36 – 45:42).

JP: Okay, er, hold on just a second.

RM: Okay.

JP: Sorry, technical difficulties.

RM: That's alright.

JP: Okay, erm, so, er, May We Help was very, very helpful with, erm, hold on just a sec.

RM: Alright.

(Pause in recording 45:55 – 45:58)

JP: May We Help was really, er, kind of integral. I live in Pennsylvania but we had the Camp in Cincinnati and we had it in Cincinnati because of them. Erm, they were willing to come in. There are a number of the engineers or volunteers, erm, who were willing to come in so we needed numbers, we needed people - dedicated, we needed erm, expertise and erm, so they were willing to come in and work with the kids. Er, and without that, we couldn't really have developed the devices. Er, what I would prefer, now they were volunteers so they were also working their own jobs at the same time. Er, a lot of them just didn't sleep that week. So, they would go to their regular job, er, take a longer lunch break, come in, meet with the kid. We spent, erm, quite a bit of time the, the very first day, in fact, really ideally, it's an hour with each child that first day. And erm, and then they developed the device based on that meeting. And then they bring it in the next day and it's never right. Sometimes it's so way off-base, the parents are like: 'Ahhh, this is never going to work.' You

know and then we say: 'Okay, this is how this could be better.' And erm, and then they go from there and they, they build another one and the thing is they're building these things at night, when they're supposed to be sleeping. And, er, so, by the end of the week, these poor guys – they look like death warmed over. Erm, occasionally, there have been one or two engineers who just completely, er, they just took the week off work. It, it was on them. There were some companies that gave them, erm, a day or two off and, and actually, er, paid them anyway as if they were working and they called it a donation, erm, and then took a tax right off for it, er, and that was wonderful too. Erm, so, what I would say, those engineers were integral. I could not have done what I needed to do without them doing that. Erm, I can't build these things. I don't have, er, wait hold, those 3D printers, erm, and I don't have the engineering expertise. I can sort of cobble something together and there was even one student who left their device at home one day, when they were coming in for lessons to their private teacher. And she took the trash in the back of her car and built a device for her son, very quickly, and she did a really great job and it worked almost as well as the actual device that was, you know, officially made, which I found stunning. First of all, that there must have been that much trash in the back of her car but also, that she was able to be so creative and do something with it. I would like to think that I could have done something similar but it was pretty impressive what she put together. So, erm, I tend to be the music teacher and not the engineer.

RM: Yeah, sure. Okay, great. Erm, just one final question, erm, because I'm moving onto, er, a research question on advocacy. Er, so, from all of my work, I'm hoping to create a central online database for, er, adapted repertoire, technique advice, erm, you know, prosthetic devices, er, adapted instruments, erm, to be in, so just in one central place, so people can, er, look at links and see: 'Oh, this musician is doing this for this instrument say.' Erm, would you advocate for, er, this for, er, aspiring [**Absolutely**] musicians and [**Yeah, absolutely**] organisations as well, yeah, yeah?

JP: Yeah and I think probably the thing to do would be, and I'm sure you thought of this as probably what you're going to do, reach out to every organisation that works with kids with limb differences or, you know, adapting of any kind and, and say: 'Hey, would you, you know, put my link on your website.' And, erm, we had done that with some other, other groups in the past but we had actually had the same idea. Erm, I am not the research person of, of the, the team that we have. It's actually my co, er, call it, co-owner, co-director, codirector, erm, Deb Amend, she is really into doing the research part and has done a bunch of the research. Erm, and she, we had talked about, you know, we wanted to have this, this separate entity that we could link to, er, that would just pull everybody's research in and all these different places you could get the research and. But then we really started thinking about it and it seemed overwhelming. Because you, there are constant changes being made, discoveries being, you know, you even saw at the OHMI conference; all of those, all of those neat ideas that everybody was presenting, that's not something that you can just find in one place. A lot of that I'd never heard of before. So, erm, if you wanted to put something like that together, I'm sure, not only our organisation, but any organisation that works with limb differences and, and musical instruments and, boy, that would be such a service to parents.

RM: Yeah, yeah. Well, that's the idea but yeah, I have to see how it goes because as you say there's so much work that goes into it but that is the plan.

JP: Well, yeah and, and the other thing is, erm, is the thing we, we, always struggle with is, you know, we have clearances for our children, our students to be up on our website. We have forms that people signed and whatever, erm, you know, and that I would imagine that would be a hard thing. Because like you said, when you can physically see something, when you can watch a video or you could look at a picture, that is worth more than a thousand words in this case because of the whole Same/Different scenario.

RM: Yeah, sure. Okay, great. Thank you. Well, that's everything, erm, but if there's any further comments you want to make, feel free. [Laughs].

JP: [Laughs]. Erm, I would say, I started to talk about, er, how children with limb differences are a little bit different from other kids and that is because their whole lives they've had to adapt and they're the final authority when it comes to the adaptation. So, when they're two years old, other two year olds, you know, they have a question, they can't do something, they look to their parent, the parent says do it this way, demonstrates, the kid does it, it's successful and there's that trust that is built. 'Ah, I had a problem, Mommy knew how to show me how to do it, Mommy fixed it, now I can do it, I trust Mommy and when I need to do something and I can't do it, I can trust Mommy.' You know, there that's, that's the whole bonding cycle, right? Trust attachment cycle. So, erm, however, limb different kids. They say: 'I can't do this.' And the parent says: 'Er, well this is how I do this but you can't do it that way. So, er, well, let's problem solve. Whoops, this doesn't work. Okay, let's try this. Oh well keep working at it. Oh, you know, you might not be able to do that till you're older or maybe never.' And that trust attachment cycle is broken and that happens over and over again and the child learns that: 'Well okay well, Mommy can't help me do everything I want to do just like everybody else, at least Mommy keeps trying. But this teacher over here she has no clue. In fact, she tells me I can't do certain things that I know very well I can. So, I learned that I really can't trust teachers. I can sort of trust my parents but the only person I can trust all the way is me. Because I'm the one who comes up with adaptations that work for me.' And not necessarily because they do but because whatever adaptation they do come up with, that's the end result. There's nothing further to do, nothing more to look up to. That's all that's possible in the eyes of everybody around them because very few people have the time, even parents, to think about what their child is experiencing to the extent that they're able to kind of come alongside sufficiently, if it's a Difference. So, that child develops a stubborn streak, a self-reliance and a lack of trust, especially where teachers are concerned, that is really hard to overcome when you are dealing with teaching a child a stringed instrument, which is like I said a really difficult thing to learn. So, you can say to that kid: 'Trust me. I know what I'm doing. You need to hold your hand this way.' And they're going to not trust you. And they're not going to do it. They might do it in the lesson because they might be a polite kid. But they're not going to at home and, erm, and they don't believe you. They don't believe that you can help get them to where they need to be. They believe that only they can help themselves and that is a real frustration. Er, not a, a emotional frustration but it is a hampering when it comes to teaching, that is a real tangible issue and when you are teaching this particular group of people. And I can say that and experience from working with my own kids who all have different personalities and that, that particular trust issue comes into play, erm, only mildly because I have worked very hard to build up my children's' trust in me in telling them what they can and can't do. And it also

helped that I worked with another kid that didn't have any arms – erm, George Dennehy. I worked with him first and then I worked with other children and I could tell them: 'Well, George can do this. So, I know you can do it.' And, you know they'd roll their eyes but that's, that's where the trust issue comes in. And they say: 'Okay Mum, I trust you because I know George can do this. I've seen him do it.' And, you know, occasionally, you'll get the very typical: 'Yeah well, I don't care if he can do it. I can't do it.' But that's a normal child response, you know. 'I know Yo-Yo Ma can play this, this way, but I can't do that.' Well, that's true you can't do it now. But he has ten fingers. You have ten fingers, so it's possible. All you've got to do is put the work in and then they kind of nod their head and go: 'Okay.' And get on with it(?). Well, if you don't have that trust or if the kid, you know, usually children that come from trauma or trust issue backgrounds really do struggle with that. And I have found that that much more than the actual limb difference is what keeps students from learning. So, I would say a really good teacher of kids with limb differences, also needs to have some training in trauma and attachment issues.

RM: Right, yeah, yeah. Okay, great. Thanks for that. That's lovely. Okay, that's it pretty much. So, thank you for your time. It's been brilliant. Erm, so, what will happen now is I'll, er, transcribe this and I've got to take all the other interviews and every other piece of research data, erm, so, it could be six months — a year down the line even, that I'll, er, send you a transcript of what's been said, erm, but actually just what will be used in the final thesis, erm.

JP: Okay.

RM: And then, all you'll need to do is say, er: 'Yes I'm happy with that.' Or you say, erm: 'Yes, but I want certain amendments.' Or you can say: 'Sorry, I don't any of this involved.' And you don't even need to give a reason but that's basically what will happen. That's all.

JP: Oh, thank you. Okay, that sounds great.

RM: Okay, great. Okay, thanks for that. Lovely.

JP: Okay. It was nice speaking to you with this morning, Robbie.

RM: Yeah, you too. Thank you. Yeah, enjoy the rest of your day.

JP: Okay, thank you. You too.

RM: Thanks, bye.

JP: Bye.

(Ends at 57:47).

Appendix 7

Commences at 03:48

RM: Hey, Hello.

JB: Hi.

RM: Is this Jason?

JB: Hey, how's it going?

RM: Hey, not bad. Yeah, so, it's Robbie. I'm okay to start the interview now, if you are?

JB: Uh, you're breaking up a little bit.

RM: Okay, so, er, is that any better?

JB: Yeah, I can hear you now.

RM: Okay, great. Uh, right, yeah, okay. Are you still okay to start the interview now or do you need a bit of time?

JB: Oh yeah, no, that's fine.

RM: Okay, great. Um, so just to begin with could you state your name and maybe just a brief description of yourself.

JB: Uh, my name's Jason Barnes and um, I'm a drummer and an amputee.

RM: Okay, great. Thank you. Uh, so, just to move on to the importance of visual media. So, the question I've [got] is how important is visual media in presenting yourself and your music?

JB: How often do I use visual media?

RM: How important?

JB: Uh, do you mean like visuals or...

RM: Yeah, so, maybe, through videos, speeches, uh, maybe, uh, press, so articles, stuff like that.

JB: And you said how important?

RM: Yeah, to you.

JB: Is that a three-part question or, I mean, a three-answer question or very important, medium or how do you want me to answer that?

RM: Yeah, very important, important.

JB: Um, yeah. I think it's important. I don't know about very important. Um but yeah, it's important.

RM: Sure. Okay, thank you. Um, so say with a lot of documentary stuff I've seen it's been, er, your story's been centred around your accident. Um, so, there's been stuff like that where you've talked about 'pink flash' say and I was wondering with things like, I mean, showing your drumming for the first time after your accident, do you think that helps audiences get an understanding of your story and your helping them in their particular situations?

JB: Yeah, sure. Yeah, definitely.

RM: Okay, um, and also with a lot of the things they describe you as being THE 'world's first' or THE cyborg drummer. Um, do you feel that's a good form of marketing for yourself or um, would you prefer to known as a drummer?

JB: Um, I mean, it's definitely a good form of marketing – um, I mean, I am just a drummer. But, yeah, I mean, people, the media coined me that and it kinda just ran. So, uh, it works. People hear that and they know what it is. So, it definitely works.

RM: Okay, sure. Um, do you think, er, so the overcoming is sort of, er, a public expectation of your story, so, you need to talk about it your accident because they need to understand how you play drums again?

JB: Um, I mean, yes and no. It just really kinda depends on, on an event I would be at. But I mean, yeah better to explain my story. Yeah, it definitely does but normally, I would prefer just to perform, um, without some long speech or intro, um of things. But I mean, it, it just depends how it goes. Like are people coming there to see me? Are they reading a pamphlet beforehand? Do you know what I'm saying? [Yeah, sure, sure]. If it's just, if it's just some event where they came across it, then, then I mean, maybe, maybe a 20 minute or 15-minute intro on explaining what's going on and how, er, prosthetics work etc, might have a better understanding but.

RM: Okay, sure. Thank you. Er, I just wanted to, er, thoughts as well, maybe, uh, with the Georgia tech stuff in particular that the focus is on that particular prosthetic with the two sticks, um, would you prefer more instances where you could talk about the prosthetic you made yourself when you got back into drumming?

JB: Um, so, typically, the prosthetic that I play with most of the time – I'm not sure if you've seen that prosthetic or not – yeah, so there's basically a starter one, then the first one that I made, that I played with, then the two-stick robotic one made by Georgia Tech. Normally, I play with my prosthetic because the two-stick one is owned by Georgia Tech

and it becomes difficult for me to use it or take it anywhere etc. I'm in the process now of funding another project where I'm essentially taking the same technology that's in the two-stick prosthetic and turning it into a one, single-stick prosthetic and just using EMG sensors, uh, to capture the motions that I want it to capture. [Would that be more...] Uh, [Sorry, carry on] Go ahead.

RM: I was just going to say would that be more, not as pricey as the ones, it would be less of a cost to do that.

JB: Less of a, but to use one stick?

RM: Yeah, to use the one stick.

JB: Uh, yeah, I mean, I preferred one stick in the first place. The whole two-stick thing, uh, was kind of suggested. Well, it was suggested by the National Science Foundation [The funders] um, and they wanted to see basically, one stick, um, be controlled via EMG and another stick use the artificial intelligence aspect, um, to develop rhythms by itself and can play rhythms by itself and basically, the only way for me to have the arm funded was to say yes to that. Uh, yeah, so, the two-stick idea was never my idea. I essentially wanted the one-stick in the beginning but, uh, that's how it kind of worked out. But it's great now because I'm, I've got enough funding from, from, various people to develop a single stick version. So, I'm pretty excited about that.

RM: Yeah, sure, so, um, would some of that funding would come from crowdfunding as well, would it?

JB: Um, well, yeah. I started a Kickstarter a while back – it probably wasn't really the best platform to do it. But my reasoning behind it was that with Kickstarter, you know, there's a requirement to follow through with the project and actually develop something as opposed to like a GoFundMe where, you know, I can say I need money for anything and then use that money for anything else. So, that was my reasoning behind using Kickstarter but, uh, the project failed but it didn't get enough funding but, (I am, I kind of have a private backer right now, I signed an NDA at the moment, I can't really talk too much about it.)

RM: No worries. Um, so, with the one-stick, obviously I know you didn't want the twostick but you wanted the one stick. Was that because you wanted, were there certain issues with your initial stick that you wanted fixing say?

JB: Wait, ask the question again.

RM: Sorry, with the, because you said you had the one stick before the two-stick idea, was the, for you to get benefit, was the idea that you get more control of the one-stick when you play?

JB: Yeah, yeah. I mean, the idea was that the prosthetic I developed myself it didn't use any robotics or anything. I kind of just used basic, basic laws of mechanics and some

leverage, uh, and a spring. And it worked but I, I couldn't really play any really fast, uh, rudiments, um, or play, like different, like jazz swing, I couldn't play it at a certain speed, uh, because I was limited on how that spring and everything bounced and, uh, so the idea was to develop a one-stick version that would, using EMG, uh, etc. and then I could essentially flex my muscle and then the stick would, would act as, as, my fingers and wrist. And yeah, so, then that's what we developed with the two-stick version but it has two-sticks and, you know, a bunch of other unnecessary technology.

RM: Sure, um, with your, er, original one-stick prosthetic, was that fairly cheap to make or was it through a company?

JB: Uh, it was through my prostheti[st], through my prosthetic company. [Right]. And it was, I mean, if I was to remake it now, it would probably only cost me, you know, maybe a thousand dollars. [Right.] Uh, but what I had made the first time, it was, it was close to four grand. [Right, okay, sure]. Because some of the parts were through a company, the carbon fiber socket is fairly expensive and it's made at the prosthetic office as well. Um, but yeah, redoing it now would be fairly cheap. Probably less than a thousand dollars honestly.

RM: Hm, okay. Thank you. Um, so I was going to move onto the, actually I'll move onto the idea of, did you ever have an idea of adapting the kit itself without having to use another stick?

JB: The idea of adapting what?

RM: The drum kit itself so you'd be able to play with just one arm or did that not really enter your mind?

JB: Um, I mean, I did. I was familiar with kind of what Rick Allen does. Cos his arm, his amputation is a little higher, well a lot higher. But, uh, I kind of just decided I wasn't really missing that much. It's essentially just my hand and I liked the idea of, um, of prosthetics or technology giving back, um, something, you know, something like a Cyberpunk kind of, kind of vibe. But yeah, I really like the idea of prosthetics more so than, um, than just adapting.

RM: Sure, yeah, okay. Um, so with the, I suppose with the two-stick as well, but with the one-stick, how long did it take you to get back to maybe a level of musicianship that you were happy with I would say?

JB: Um, about a month.

RM: Really?

JB: Yeah, I mean, it was a little longer than that for me to be really, really comfortable but about, about a month was about how long it took for me to like, kind of realise, like it's just going to take a little bit of practice of learning how the prosthetic works a little bit. But, yeah, I mean after a few weeks, I was, I was feeling confident again I guess.

RM: Sure, okay. Um, So, I saw another Georgia Tech project where you were using is it the Bebionic hand with ultrasound to play the piano?

JB: So, I'm not using the Bebionic hand. Basically, the reasoning behind that is for me to have done that would have hacked it. [Right, okay]. It would have voided warranty etc. So, we used, um, an OpenBionics hand which is uh, they're a UK-based company that uses 3D-printed technology to 3D-print limbs for children mainly. [Right, okay, sure]. But they, uh, have, it's all like open source, well most of it was. Uh, and their hand online, you can just download the file and, so, we just 3D-printed a hand and used, um, that because it had individual motors we could use, um, that would control, you know, five individual fingers. [Sure, yeah]. Yeah, it, so, that was easier to do than just the Bebionic. We didn't want to void the warranty in my hand [Laughs].

RM: Right, sure. Okay, um, did you find, did you ever get to a level with that, that you felt comfortable playing the piano on that for extended periods of times or doing things like chords and some melodic lines?

JB: Erm, no, not quite. That was still extremely like experimental technology because, uh, no one has really, I guess, that I know of has had success in using an ultrasound sensor to operate five individual fingers. [Yeah, sure]. Um, and so everything was very slow like, it was, was extremely accurate but it was, uh, I could only use, I could only do one finger at a time. We weren't far, further enough along to, um, to make it do gestures or chords. Uh, and then again, it kind of has a second of latency so, no that, that was very experimental. But we sparked the idea in a lot of, of bigger prosthetic companies now, so, that's a good thing, I guess.

RM: Yeah, okay, great, yeah. So with, with the Bebionic hand, is that more, uh, for, for everyday purposes?

JB: Uh, yeah. So my Bebionic is pretty much for just daily, uh, chores and, um, activities, you know, going out, um, sweeping, uh, I don't really do the dishes like that – I would usually use one hand because the Bebionic is not waterproof. But you know, making food etc. uh, it's good for that. Uh, it's, it's kind of cosmetic, uh, appearance as well – it, it looks like a hand, you know, an anatomical hand. Um, but anything more strenuous than that or extreme like, um, maybe working out in the yard or, you know, construction or something like that, I would use, uh, my myoelectric hook, which is basically like a body-powered hook. I don't know if you've seen those. I'm sure you have.

RM: Yeah, was that your original prosthetic that you got?

JB: Uh, well, no because now I have a myoelectric arm and a hook that, a myoelectric hook that you can get for it has, uh, a very wide level of strength settings. [Right]. And I also have, um, an electronic wrist rotator. So, I can kind of rotate on command and open and close, uh, different levels of strength on command with that hook as well as the body, the body-powered hook, um, essentially does the same thing but everything's manual – if I want to rotate the wrist, I have to press the button, then rotate the wrist with my other

hand. Um, and then the way the strength settings work on a body-powered, um, prosthetic usually just use like a rubber band system.

RM: Um, yeah, okay. Uh, so, sorry with the Bebionic hand. Is it true that because I saw you on the Doctors TV show was that actually funded by them through the show?

JB: The Doctors TV show?

RM: Yeah.

JB: Yeah, so, I think it was a collaboration of them and my prosthetic company and, uh, Bebionic. Uh, and then, er, later on, I eventually got my insurance company to pay for another one for me.

RM: Okay, um, so, do you believe one day, uh, if there was specific technique advice and, uh, repertoire for alternative methods to play drums and etc. um, so maybe something where you show how you flex your arm to play the piano and drums, do you think that would be possible to showcase that to people in a public forum say?

JB: Uh, if something was made, um, to operate efficiently enough?

RM: Yeah, yeah.

JB: Oh I, I mean definitely. I, getting that kind of technology out into the world and available to people is kind of extremely necessary. Is that, am I answering your question?

RM: No, no, yeah, that's great. Thank you [Yeah, yeah]. Um, so I was going to, er, move on to, er, there's this thing called the test of authenticity where it's basically audiences, genres of music expecting certain instrumentation and prosthetics, erm, have you, how have you found the audience reaction to, to your prosthetics that you use to perform?

JB: How have I found my interaction to the prosthetics?

RM: How, audience reactions to your prosthetics been?

JB: Oh, the interactions?

RM: No, no, sorry, how the audiences react to you playing on stage with your prosthetics?

JB: How do people react?

RM: Yes, yeah.

JB: Oh, sorry you were breaking up there. [Oh, sorry]. Uh, I mean people, some people are kind of against it with the two-stick, uh, prosthetic. Obviously, I mean, I'm against it, as a drummer, I am especially. Uh, but, er, most people are just kind of amazed and marvelled about what technology can do, uh, with things like that and, er, I guess some, some

people have actually enjoyed some of the performances that we do too. So, um, overall, I think a lot of people enjoy it but there's definitely certain people that are maybe worried that, um, robots are, we're trying to make robots take over music or, um, it might be cheating because it has two sticks, um, etc. which is again my reasoning behind the one stick.

RM: Sure, okay. Um, so, moving on to, uh, so influence of people. So, people with similar impairments and er, you know, issues with playing the drums ever spoke of you influencing them, be it in music or outside of music?

JB: You, you said: 'Have they?'

RM: Yes, yeah or have you found many examples of people saying that?

JB: Um, yeah, I mean, all over the Internet, there's a few instances and, and, um, I think, I believe it was Moscow, Moscow, it was in Russia; it was Moscow or St Petersburg but um, the performance there that I did and I guess it had been about a year or two after, you know, some of the first videos of the prosthetic and things like that, you know, had come out and there was another amputee kid there and kind of, you know, came up to me after my show and told me that, er, he'd been following my story, you know, since it happened and I've inspired him to not to give up and follow his passion to and, you know, he, he wanted to play guitar and all of these things. And yeah, I mean it's extremely awesome. [Sure]. To inspire people like that I guess.

RM: Hm, great. Actually, so, you mentioned guitar. I saw you played guitar, er, before your accident; have there ever been any interactions about you trying to play guitar again with prosthetics?

JB: Um, I've talked about it. Uh, I've never really tried to as of yet. Uh, but there's definitely readily available prosthetics out there that, er, are available that you can buy through, through a prosthetic company that, I, to my understanding work pretty well. Um, there's a fairly famous, er, amputee, er, guitar player who went to Atlanta Institute of Music a few years before I did. Er, Jason Williams, I believe is his name. Jason 'Lefty' Williams is his name. Er, and he's really good too. He's, he's extremely good. Erm, and I actually know a few amputee guitar players that are just completely amazing.

RM: Oh, that's great. Uh, so I'll just move on to, obviously I've talked a lot about Georgia Tech, how they've helped. Have there been any other major organisations that have helped with your progress?

JB: Um, Google. [Yeah [Laughs]]. Er, I don't know, I mean some of the tech companies that make, uh, the technology used but as far as, as funding things and stuff like that, it's pretty much just been, uh, Georgia Tech, National Science Foundation and Google that I know of.

RM: Yeah. Did the, So, the Atlanta Institute of Music got you in touch with Georgia Tech with Gil, didn't they?

JB: Uh, basically I went to the Atlanta Institute of Music with my prosthetic that I made. And er, very early, in the beginning, I had a pri[vate], basically you have a private lesson every week. I had one of my lessons with my teacher and he was curious as to what I could and couldn't do and so I kind of explained everything to him. His name was Eric Sanders, if that helps at all. But he, yeah, basically I explained to him what I could and couldn't do and it kind of, and I also told him that I had this idea of developing, you know, a robotic version that would, er, essentially, you know, do exactly what the Georgia Tech one, you know, does. But he was kind of intrigued by my idea. Then, he reached out. Um, he told me that he taught lessons to another student. I mean another, um, person who wasn't a student at the Atlanta Institute of Music; they were actually a student at Georgia Tech and he just taught private lessons to them and they worked, um, basically with someone in the Music Technology department and that kind of bled to the idea, um, of Gil following through with the idea. Gil, Gil Weinberg, the, er, the Head of the Music Technology Department reached out to me after he had heard about the idea from a student of his essentially.

RM: Yeah, okay, great. So, have there been any organisations, er, that you have collaborated with yourself that have helped any other musicians with any form of impairments or disabilities?

JB: Um, TRS prosthetics is a company that makes like activities specific devices and they do a lot of, um, in fact they're the ones that actually make the, um, guitar prosthetic and they make the [very furthest?] of a drum prosthetic that, um, which doesn't work very well but um, they actually make a lot of awesome things. So, no, no, er, no judgement on their part because they've done a lot. But, er, yeah, I mean, there's, other than that there's been actual prosthetic companies that fit people for prosthetics, you know, like a clinic. Uh, but that I know of, er, as far as doing something like developing a prosthetic arm or anything like that, I don't know of anyone else.

RM: Okay, so, um, you're doing very well. Moving on to my final question, you've done a lot of information. So, I've got a proposal myself in the future where I'm thinking of an online database for, you know, technique advice or certain prosthetics, adapted instruments, you know, you talked about your prosthetic that cost four thousand dollars originally, probably cost around a thousand now, um, so, basically, it's a, you know, anyone can access it, um, public information so just people know, would you advocate for this for aspiring musicians?

JB: Oh, 100 per cent. [Okay, great]. I've already planned that, you know, I've, I've basically let everyone know that if anybody; all the kids that have reached out to me too have asked me, you know, how my prosthetic is made, this and that, um, even the basic one and I've freely, you know, I'd give anyone, you know, the whole designs of everything and how to make it. And even my idea on how I make the, the next version or, which is a little bit better, um, and cheaper because, you know, people in other countries, even like third world countries and stuff like that, obviously can't afford even a 10,000 dollar prosthetic so, um, and they don't have the insurance to help for that, so, yeah, I'd love to, to, to advocate for something like that or even be, be a part of it.

RM: Okay, great. Alright, thank you. Well, everything you've done fantastically well. Thanks for answering all of my questions. Erm, so from now, er, I've still got more interviews to do so maybe in 6 months to a year's time, erm, I'll be on my final thesis and then I'll be incorporating some of what you said into there and I'll will email you the stuff that I will use. Erm, and then, if you just email back saying, you know, yeah, it's fine to use all of it or if there's a certain bit you don't want included, I can get rid of it. Or if you want me to make a certain change, erm, to it, just when I send the email, just let me know and that will be it basically.

JB: Awesome, yeah,

RM: Yeah, okay.

JB: Glad too.

RM: Okay, great. Thanks for your time.

JB: Yeah, man. No problem.

RM: And enjoy the rest of your day.

JB: You too.

RM: Okay, bye.

JB: Bye.

Appendix 8

Commences at 00:50

LW: Hey buddy, How's it going?

RM: Not bad. Are you alright?

LW: Er, can't complain.

RM: Excellent. Er, Great. So, if you're happy to start the interview, we can right now.

LW: Er, sorry, say that, my GPS was just telling me where, where to go.

RM: Okay, no problem. I was just going to say that if you're good to start now, I'm good to go.

LW: Yeah, I'm good.

RM: Okay, great.

LW: [Inaudible but incidental].

RM: Okay, great. Alright, so, just for the record, would you just be able to just state your name and give a brief description of yourself?

LW: Okay, er, my name's Jason Williams, erm, publicly known as Lefty Williams. I am, er, 45 years old; born with one hand and um, sorry just turning off the GPS.

RM: Of course.

LW: Um, I was born with one hand. Started playing guitar at the age of 4. Invented a pick that fits on my arm and allows me to pick individual notes. When I was 6, I had a little bit of help from my grandfather in designing it. Um, my mother's father. Um, and er, kind of developed it over the years it just sort of changed as I got older. I found newer and better ways to, you know, attach the picks; er, make it a little more stable and sturdy [ier]. Um, I've been playing in bands since I was 7 years old. Um, when, in, in 2005, I, er, went into being a full-time touring musician. And between 2005 and 2015, or I guess really 2017, I did about 2,500 shows. Between 2,500 and 3,000 shows. Um, I, er, been featured in a bunch of guitar magazines like Vintage Guitar; er, Guitar Player; um, trying to think of any other ones I've been in. Er, and then a lot of, you know, music magazines like Hittin' the Note and Relix and other things like that. Um, what else do you want to know?

RM: No, that's fantastic, thank you. Um, so, I suppose I'll start with the building of the pick. Um, so, how long did it take you to build that first plectrum?

LW: Um, you know, I was 6 so I don't know if my memory is super reliable [Laughs]. [Sure.] Er, but I know that, er, what I did was take apart one of my prosthetic arms. Er, I used the shoulder harness to sort of, you know, I'd use that as a [strong mat?] so that the whole thing does... [Inaudible – 03:47 – 03:49] the notes and um, the guy that made my prosthetic arms, um, had built, a, a pick for a bass guitar player here in town that was kind of like a leather cuff. Um, then, you know, the, the cuff went around the arm and then it had a little strap that fit around the back of the elbow. Um, and um, then, he didn't, he didn't use a, you know, like, a, a publicly available pick; he sort of made his own out of like this [art?] piece of plastic. And then he riveted that onto the leather cuff and, um, when I tried the leather cuff, it just did not work for me at all. It was just too loose; I couldn't get any accu... accuracy with it. And, um, so that's when I got the idea to tear apart one of the [artifices?] from one of my arms and, um, used that to attach to my arm. And I just sort of put the little, little metal ring round the, the end of my arm and put the, er, the, er, nylon webbing strap around that side of my arm; and then I, er, I don't remember how I attached it the first time to the strapping. Er, it went through a bunch of iterations; I mean I know I tried stapling it on at one point; I know I used paper clips to hold it in place, um, you know, just wrapping paper clips around the, around the webbing. And then, um, eventually, I was playing in a band in the, in the mid-90s, um, and the second guitar player in the band, er, you know, got it in his head; I think we did a gig and maybe I forgot my pick at home or something. [Right.] And, the, the second guitar player in the band got it in his head that I should have multiple back-up copies so that I would never do that again. And he kind of talked to his mom about it, his mom was, you know, really good at like sewing and things like that. She wound up, I think she wound up making me three or four different picks. And when she made, when she made it, she was the one that came up with the idea for using rivets to attach it to the strapping. Er, and that has been, you know, what I've used ever since.

RM: Yeah, sure. So, I'm presuming, er based off this, that it was all very low-cost and very inexpensive?

LW: Oh yeah. No, I mean, I think a pick cost me about 10 bucks to make. [Wow, yeah, yeah]. I mean, not counting the tools, you know, there's probably 20-30 dollars worth of initial investment of tools but, you know. Well, probably more that because you need a, you need a little hand bidding tool, um, then, you know, I use a pair of [lineman's fires?] to, to hold the pick and warm it up so that I can bend it. Er, you know, the [lineman's fires?] are probably 30 bucks by themselves. Um, so probably about 50-60 dollars worth of tools on the front end. And, er, the materials, er, involved in making the pick, you know, [like a pick?] probably no more than 20-25 dollars.

RM: Right, yeah, sure. So, do you find that you are still modifying it even today?

LW: No, no, I mean I really like the cut. You know, the way it's made now, it really works for me. Um, you know, the only thing that's, you know, difficult or tedious is that, you know, the picks, the picks wear down over time and I'm a fairly aggressive player, so I probably wear picks down a lot faster than other people do. Er, I have to use a heavy pick, I can, I actually have my own, um, er, well, I mean I don't know technically if I still have an endorsement deal with them, since I'm not performing full-time anymore. But er, the er,

oh lord I can't think of the pick company now. [Alright]. It's been like two years since I talked to them. Er, I can see their logo; they're the ones that have the [keyhole?] logo. [I think I'll be able to find it, don't worry]. Yeah, I used, anyways, I used their picks; I like the 1.14mm picks. Um, I don't like to go up to a 1.25 [mm pick] because that's a little too thick. Um, and I don't like to go down to a 1 [mm pick]. The 1's feel good but yeah I can melt a 1mm pick in like [2-3 goes?].

RM: Yeah. So, are they all plastic plectrums because I think I've seen things about brass picks as well that some people are using for stuff like that?

LW: Yeah, I went through a phase where I was trying to not have to replace the picks. So, I tried, I think, brass picks for a little while and I liked the tone of the brass picks; they're a little darker sounding, I mean as odd as that might sound, the brass is actually a little darker. Um, but, but, those things turn into razor blades. And I once sliced my finger open, er, on, on more than one occasion by accident, just by barely touching the pick. Um, after using it for an extended period of time, so I don't use those anymore.

RM: Fair enough, yeah. Um, did you find you had to modify the guitar in any way for like using light gauge strings or changing the tuning at all?

LW: No. [No, nothing at all?]. I mean, I never had to modify a guitar. [No, okay]. Er, the one thing that I do is when I'm playing, er, Gibson guitars, um, I move, I, I flip-flop the volume and tone pots [knobs] around so that I can reach them with my arm. Um, but at Gibson, they do, er, they do the, er, two that are closest to the neck of the guitar, the volume pots and the two that are at the back end of the guitar are tone pots. So, with Gibsons, what I usually do is, er, I, I take the, I make the two top ones volume pots so that I can reach them because I never really, I don't really use tone pots to change my tone when playing. Um, in fact, I really don't touch the tone pots at all. But, um, but yeah, with the Gibson guitars, I make the volumes on the, I, I just move them so they're on top.

RM: Yeah, okay. Fair enough. Er, right so now I'll move on to, I was going to move on to the visual media side of things of presenting yourself. So, um, a lot of my research has come from your website, I was wondering if it's still active, your website?

LW: Um, you know, a year ago I decided that I really didn't need to have a website anymore because I wasn't touring and there was no good reason to have it up. Um, you know, I probably should relaunch it, um, just because I, I still occasionally get, you know, calls from people all over the world asking me how I make my picks and, um, you know, so I, I think if I do relaunch it, it's mostly going to be [promoted?] towards helping people with that. Um, you know, more so than me getting out and playing, you know, I may have a calendar because it, I am starting to miss it; I am starting to miss playing again. Er, it's been, I did my last show in [August of?] 2017. And, um, that was when I officially, you know, ended my touring career. Er, I have no intentions of going back into touring or anything like that because I, I run a very successful business and it monopolises almost 100% of my time. Um, but, um, but, you know, I am kind of missing, you know, getting out and playing. So, I've kind of done a couple of shows here and there; sat in with a few people from time to time and er, you know, I may, I may join a group as, as a hiring gun

and just do a few shows locally around Atlanta. Er, you know, who knows? I don't like to say where the future's going to end up because nobody really knows.

RM: Yeah, sure. Okay, thank you. Er, another thing I was going to mention was with your music video for 'Let It Roll On', it shows you doing a lot of, erm, things with one hand such as: tying shoes, which I saw you did in a separate video for someone; and things like shaving. Do you find that these and it was, I know it's very much you being on tour and doing things, do you think that helps people, seeing things like that or have you had messages that have said that?

LW: You know, I, I do. The thing is that when I, when I did the video of me tying my shoes, the, the, it really wasn't about showing that I could tie my shoes as a one-handed person, um, or a disabled person. It was, it was really just me doing like a day-in-the-life, you know. And, um, and so, the, the point of that was, you know, kind of what it was like to be more, what it was like to be on tour and, you know, always on the road and, you know, always moving from town to town and, you know, just sort of what a day was like in my life. And, erm, and then I started getting inquiries from people going: 'Hey, you know, we saw you did that in the video and, you know, we were trying to teach our kid how to do it, you know, how do you do that because it's not long enough of a, of a clip to really see what you're doing. And, erm, that's what kind of led me to do the video of me tying my shoes because somebody specifically asked, And, er, and, you know, that's, that's sort of how that came about. Um, you know, I, I don't really see myself as being an inspirational type of person, um, I get told that I am a lot but, I don't know, that just sort of feels weird to me. Um, you know, I just, when I was born, the doctor told my parents, you can raise him to be special or you can raise him to be normal and whichever one you choose is how he's going to be. Um, my parents just raised me to be normal, so I don't really see myself as any different than anybody else. Um, you know, honestly, to the point where I was in my 20s before it ever really occurred to me that I only have one hand. You know, I was, I was looking in a mirror one day and I, I happened to notice my arm and went: 'Man, That's [Laughs] that's crazy.' You know, I've never really noticed that I only have one hand before. I mean, you know, obviously I grew up with it; I'd always known that I only had one hand but, you know, it didn't really hit me as being a real thing until that point. Um, just because I never thought about it. Um, and, you know, to this day, I still, I don't define myself by being a one-handed person or, I don't even consider myself to be in any way disabled, any way shape or form. Um, you know, I, I just don't think that way.

RM: No, no, that's fair. Actually that moves quite nicely because, er, I remember seeing a new report with you, er, advertising your 'Not A Gimmick' tour. I suppose that leads in quite nicely with what you were saying just there. Do you think that was a way of people recognising what you are doing is not a gimmick and you are a legitimate musician?

LW: Erm, you know, that whole thing really came about more because more and more people talk about me having one hand. [Yeah.] Erm, and I, I kind of wanted to make the statement, you know, kind of get off the hand, you know, that's not – pay attention to the music. [Laughs]. You know what I mean? [Yeah, yeah]. Um, no, that was really more about, um, that's where that whole kind of messaging came from as I was trying to take control of my own narrative, And, you know, I, I went by the name Lefty because one of

my smart-ass friends in high school kind of nicknamed me Lefty. And, you know, I, when I was in bands, it always seemed like, you know, the, the rest of the band always wanted to avoid at all costs, you know, talking about me only having one hand. You know, if, if the media ever brought it up, it was like you immediately like, you know, silence; they would not talk about it, you know. Nobody ever wanted that to be any part of any marketing message or anything to get attention for the band. Um, I think most people were afraid that if, if they allowed that to become part of the marketing message, that it would become the only thing that anybody cared about. Then, so, when I started my own band and kind of went out on my [Lost connection – 16.13 – 16.15], you know what, people call me Lefty; might as well just use that name and, you know, I do have one hand; so might as well, you know, let people talk about it if they want to. And um, you know, the thing is, is years later, it, it did. It was all anybody ever wanted to talk about. I was, you know, two albums in and, you know, all the people in the newspapers wanted to talk about was, you know, the one-handed guitar player. And it was like, 'that's great but, you know, get past it, man.' I mean, that was news for my first record; now let's talk about my second and third record, you know. Erm, and, you know, that was one of the things that, you know..., [Lost connection 16.52 - 16.55] smallest of all things but one of the things that sort of made me decide that I wanted to move into a different career.

RM: Um, right, yeah. Um, yeah, I suppose I was going to ask about the website as well, when you had, all the reviews you've had when you're talking about the guitar magazines as well, do you think that was a way of again trying to kind of control your own narrative and say, you know, um, this is people, you know, this is what people think of me, this is what I can do?

LW: Yeah, I mean, it was, it was more that I'm a legitimate musician, you know, can you just listen to the music and, and, you know, judge it on its merits instead of deciding that you're interested or not interested because I, you know, because I only have one hand. Um, and to be fair, I will tell you that, you know, reviews that I got from music magazines were generally very generous and very kind, you know, they were always, you know, they might talk about me only having one hand but, er, they usually backed it up with something along the lines of the music is great, you know, you should pay attention to this. Um, you know, so they did use it as a way of, I, I think that in, in the writer's minds, I think that they were saying this is going to catch people's attention if we talk about this, but then we're going to legitimise you by saying you write great songs. Um, and so, I think that was a lot of what they were trying to do. And I don't to, I certainly don't want to give the impression that I was like angry about it or frustrated with it, um, because I wasn't I was appreciative of the attention, you know, and I was appreciative of the fact that they cared. Um, you know, it was just, you know, there were definitely times when it felt like, you know, if I didn't have one hand, would they be covering me, you know?

RM: Yeah, yeah. Er, moving on. Another point was, you were saying about people said to you that because of your lack of an elbow [meant wrist] that it actually meant that you quote unquote had a 'perfect picking technique', do you understand why people were saying this and do you agree or disagree with that?

LW: Um, well it wasn't a lack of an elbow, it was a lack of a wrist. [Right, sure. I'm sorry. Yeah, a lack of a wrist]. And mostly the reason I kept hearing that was because, um, you know, a lot of guys, you know, they move from the elbow, um, instead of from at the wrist and because I didn't have that secondary flexor of the wrist and the elbow, my arm never really moved. So, um, you know, so, I wasn't having to try and compensate for, you know, for my forearm moving up and down as well as my wrist changing positions. And I was really just moving from the one pivot point, which, you know, made it easier to have a better picking technique. [Sure, yeah.] I think that's what they were trying to say. I don't know that, you know. I wouldn't say that my picking technique is by any stretch of the imagination 'perfect'.

RM: Yeah, sure, okay. Um, I saw as well, your time as a teacher that you, it says that you taught, um, guitarists with limb differences, er, would you be able to elaborate on this at all? Were there certain methods that you used that were transferrable to them?

LW: Um, I mean I only gave a handful of private lessons to a few people with, you know, with missing hands. Er, a lady in Vermont that, you know, had me come up to her mom one time and give her a private lesson. Um, and, er, then there was a guy in Canada, that had me come up to Canada. Um, mostly, it was just conversations online, you know, via email, things like that. Um, most of the teaching that I did was at the Atlanta Institute of Music and I wasn't really teaching people, you know, that, that were in any way disabled; they were just regular college students. Then I did private lessons and a couple of different music stores around the Atlanta area. Then again, no special needs students at all, just, you know, regular students.

RM: Sure, okay. Um, so moving on to organisations. Have you worked with any, er, organisations who assisted, er, in your progress as a musician?

LW: Er, like what do you mean?

RM: Um, sort of prosthetic makers, er, just, er, any organisations that could help, er, that could help a guitarist with one hand. Was it mostly done, you know, by yourself and those around you really?

LW: Er, with the exception of the guy, guy that made my prosthetic arms when I was a kid, no. Um, you know, he, he was the only one that ever made an attempt. Um, I did try to kind of team up with a couple of different, you know, like I talked to a couple of different doctors and hangar prosthetics here in Atlanta. Um, and they were, honestly, they were just completely indifferent. They had no interest in, you know, developing a prosthetic with me or anything like that. And, um, basically I, I just kind of got, I don't know, for lack of a better term, ghosted, you know. I would reach out and kind of discuss the idea with them and then just never hear from them again, you know, never get responses to my follow-up calls. Er, but I don't wanna, you know, I don't want to make it seem like I tried a bunch of different places; I mean I think I maybe asked two different doctors, you know. So, it wasn't like I tried a bunch of different places. And my sole ambition in that, when I was trying it was to try and make something that was a little more readily-available to the general public.

RM: Yeah, sure. Um, have there been any, er, organisations that help disabled musicians that have asked for your help for anything?

LW: Er, no, not really.

RM: Okay, fair enough. Um, yeah, so, really, on to my final question because you're doing great. Um, so, a part of this project is that, er, afterwards, I'm potentially looking to create an online database for, er, certain repertoire; technique advice; prosthetics; adapted instruments, um, that could be publicly available to anyone who needs them. Would you advocate for having one central database like this?

LW: I'm sorry. Say that again. Are you asking if I would participate?

RM: I'm sorry. Advocate for this.

LW: Oh yeah, yeah. I mean I think that'd be great to have something like that where people can look it up. I mean, the internet revolutionised the world, you know, I mean it's, in many ways it's driven us apart but in other ways, it's, it's brought us all within inches of each together, you know, And, um, I mean, I think, I think having something that's easy to find online, that, you know, could help people that are looking for some kind of a solution, you know, or maybe provide them with, you know, that idea that would help them solve a problem of their own, you know, I think that that's an invaluable resource, you know.

RM: Yeah, sure. Okay, well thanks a lot. That's all my questions, er, so.

LW: Okay.

RM: What will happen, erm, now is I'll have to go away, take all this, transcribe it. Um, and then, when I'm doing my thesis, I'll, er, email, well, I can either contact you on Facebook or email you or let you know through this, just, er, that I've sent you what you've said here. Um, and then you can look at it and say, um, I'm okay with this being included or if there's certain bits you want me to take out I can or if there's certain bits you want me to tweak, I can do that as well. And then that, that will be it really. And then if you want to see the final thesis, I'll let you know where it can be found.

LW: Awesome. Yeah, just let me know. I'd be happy to, you know, help promote the project in any way that I can, um, you know, I'd be certainly more than happy to put it up on Facebook and, and share it and, er, help get the word out in any way that I can. But, yeah, let me know however I can be of help.

RM: Okay, thank you very much. So, enjoy the rest of your day. And, erm, yeah, I'll contact you at some point.

LW: Alright. Well, happy holidays and best of luck with the project.

RM: Thank you very much. You too. Bye, bye.

LW: Bye. Bye, bye.

Interview terminates at 25:26.

Appendix 9

Commences at 00:52

TM: Hey Robbie. How's it going?

RM: Not bad, thanks. Are you alright?

TM: I'm doing well. Thanks for having me.

RM: Excellent, no problem. So, if you're ready to start the interview, um, perhaps you could just begin by stating your name and maybe give a brief description of yourself.

TM: Of course. Well, my name is Tony Memmel. I am a singer-songwriter, a public speaker, a teacher, and a composer. I live in Nashville, Tennessee in the United States of America. And it is my life's mission to use the talents, and gifts, and abilities that I've been given, and the special difference that I have to hopefully impact youth and people with hand and limb differences around the world.

RM: Excellent, thank you. Um, so perhaps with the interview I could just start by talking about the prosthetic itself, um, with obviously the tape and the pick. [Yes]. Um, in particular I was going to talk about the step-by-step video you did in how you construct it. So, I wanted to know, um, how, when and how did you decide to come about with that video? Was it requested, for example?

TM: Yes. I get a lot of requests asking how I make my adapted cast, and something that I've found to be a unique challenge in the field that I work in with helping people to come up with adaptive methods to play the guitar, is even amongst, um, this community of people with differences, each difference is unique to itself. So, what I do and what I hope to do is to demonstrate with that cast that I make the videos out of and, er, show that with just a few pieces of Gorilla tape; it's really strong duct tape that you can make an adaptive cast to play the guitar. And sometimes, I help people make those casts very similarly to mine, but a lot of times, even with a slightly different hand, it doesn't work exactly the same. I happen to have an exact space on my arm that is the perfect size for a guitar pick and that does help me to make the cast that I do possible.

RM: Um, also, in the video you mentioned how, er, it was through 8 years of trial and error that you came up with, um, the cast. [Yes]. Would you maybe describe some of the materials and processes you used to get to that point?

TM: Sure. So, when I first started playing guitar, I had never seen someone play guitar with one hand before. I had never, I didn't really know exactly where to begin; I just had a hope, and a dream, and a goal and just confidence that I could do it. So, what I did is I actually had to save up to buy my first instrument. And when I brought it home to make my sound, my first sounds, I noticed that the sound I could produce with my guitar with my arm alone was just not what I heard on the radio. It wasn't what I wanted to be like. So, my hope was what if I could go around my house and construct, with the tools I have

at my immediate disposal, a cast that would help me play the guitar. So, I noticed, when I first was playing guitar, that I do have this space on the end of my arm that's the perfect size of a guitar pick. And I just thought, but it's, it's not strong like a muscle or like fingers, it's just, it's a space. So, when I actually bend my arm to play the guitar, it falls out but it does stay in long enough to, to be in place. So, I thought, what if I could secure it to my arm with some materials. So, I went around my house looking for, um, like scotch tape, we call it like clear tape that you go around, that, like you wrap a present with, um, duct tape, paper clips, glue, strings, socks; everything that I thought might help me to make the cast. And I would sit at my table with that box and just try and make different devices and, er, I started with just taking a roll of scotch tape and that guitar pick and just wrapped it around my arm [Laughs]. 10 times and, er, it worked about as well as you could imagine. [Laughs]. It made more sound, it made more sound than it did previously so, I was on my way.

RM: Yeah. Um, so do you think you've perfected it now? The, what you use?

TM: I think with the cast that I have now and the materials that I use, I am pretty satisfied with, with where it's at. There are days, er, especially when I'm on a, if you're in, you know, as a performer, you're often in situations where you have to be outside in the middle of Summer in a festival and you're sweating and that can sometimes, er, be a hinderance to the, to the adhesive on the tape actually sticking to my arm very well. So, those, those days are challenging sometimes and I have to be pretty mindful of that. Um, sometimes I'll build my cast before I even get to the show; sometimes I'll like have to make sort of in further adaptive, adaptive cast where I like, it's more just like just a backup; mine usually just uses 2 or 3 pieces of tape when I'm playing at my house, for example, but if I'm at a show like that, I'll probably have to take like a whole, like more of the roll and actually make something that works as it fits to the hole end of my arm; a little hard to describe but, um, just to try and go through those situations. So, it's a little bit situational to get back to your question specifically. It's, er, I, with Gorilla tape, I think it's a really good solution and it's inexpensive and it's something that students that I work with can go to the store and get today; they don't have to wait and go for fittings and prosthetics and everything like that. Um, and then as soon as they get it all figured out, they've grown a little bit; it doesn't fit the same and then all of a sudden, they're not that interested in guitar anymore because it's been a hard, long process, you know. So, yeah, that's where I kind of find my interests to be is to try and use what we do have to get started. And that's why I like Gorilla tape for what is.

RM: Yeah, sure. Um, have you known of, er, any casts that could potentially be mass-produced? I know you said it's difficult because, um, because there's no muscle or finger, you know, strength in the space in your arm but have you seen or heard of any like, slipon casts that you could potentially use so you wouldn't have to apply tape every single time you play?

TM: I have never seen anything, er, mass-produced. [No]. Um, you know, I, I like to think of the possible, so, it's not, it's not something I view as impossible. I do think it would be a nuanced and interesting challenge for the person that tries to come up with that. Um, it's one reason I, I like tape, especially with, with or just, you know, tape, or supplies, socks

and like just anything that can get people started with what they do have because, um, the, just the variety of hands, you know, I can be at a conference for people with limb differences and I'll have a line of 30 people who come to sit at my chair with me and to try guitar for the first time, and they have such a wide array of different hands and arms and, um, that I think it would be challenging, and I don't actually have a solution at this time. [Laughs]. But that, I think it is something that, you know, maybe somebody could figure out.

RM: Yeah, yeah, okay, definitely. I'll move on now, er, [I] saw on your website, you sell, er, merchandise with, er, your silhouette on. I just wondered how that came about? Um, was it just your own idea or was it, erm, for example, with your work with Lucky Fin Project, I noticed that they have a lot of merchandise like, you know, 'Ten Fingers Are Overrated', was it, did that inspire you or did yours inspire theirs or was it completely separate at all?

TM: Er, I think it was actually completely separate. [Okay]. The original, I've, I've been using that logo since probably 2008 or 9, if I can recall. Um, and then I just put it on just about everything, and really, it was just taking a, a picture against a blank wall and then cutting it out and Photoshopping it into that like black and white or, you know, whatever the colour of the work that we're doing happens to be. So, that's where that logo came from for me, and then Lucky Fin Project started on its own. And then, er, reached out to me as they were trying to reach especially kids in schools and churches and hospitals around, at the time, the United States, um, and asked if I would be an ambassador for the organisation. So, what I do with Lucky Fin more specifically is travel and visit those, those same places I just described: schools, churches, communities, hospitals and just connect with those families wherever I go. Their specific merchandise is sort of something that happens, um, completely apart from me and whatever my specific role in the organisation is.

RM: Yeah, okay. Um, so, also I was going to talk about the, um, Official song of theirs: 'The Lucky Fin, er, Song'. How did that, um, come about? Was it just again through you becoming an ambassador for them?

TM: Yeah, so, I was asked to be the ambassador and then, as I was touring and meeting these families, I thought it would be a really neat way to use my gifts of music and song writing to hopefully write something that I could perform in the schools and then make a video out of that and, you know, [ever?] did something easy to share with somebody who maybe just got news that, you know, from their, from their doctor that they're going to have a child born with a hand difference. And the first thing they do is start looking for it and maybe they can see kids out there who are doing amazing things and so, it was sort of this; I'll take the song and I'll make something that is hopefully easy and fun to sing and put it out there as a way to serve the Lucky Fin Project. And it's been pretty amazing how, er, that has, that simple song that started, you know, in my apartment where I was living and has now, you know, spread all over the world is something that people find in those situations I've described.

RM: Um, yeah, okay, definitely. Um, so, I'll just move on now to, I saw you did some work

with the Cincinnati Adaptive Music Camp, who I've been in contact with. Would you be able to just describe some of the work that you did for the, er pupils, well students that were there?

TM: Oh, very nice. Did you, who did you speak with? Were you with Jen or?

RM: Yeah, Jen. Yeah, I spoke to her.

TM: Okay – she's a good resource for sure. She's a really, er, strong teacher. Er, I was originally contacted by the Cincinnati Adaptive Music Camp, which eventually became a non-profit called Adaptive Music Project. Um, I was contacted because they had a student apply who wanted to learn to play the guitar but did not have a guitar teacher. And, er, the student that had applied, I had actually met at a conference years earlier. And her, her mother suggested that I'd be, er, somebody they could reach out to about possibly teaching, and I was available and ended up doing that several times with them, er, as a teacher. And then I was asked to be a part of the, the Board as it formed about to hopefully, you know, grow from there. And so that was how it came to be in the first place.

RM: Um, okay, yeah. Um, when I was talking to Jen, she was talking about some of the problems of, er, you know, because how difficult it is and the fact it had to be, er, based in Cincinnati, even though she isn't. What things do you think could be provided for them that would help them achieve what they want to achieve?

TM: The camps specifically or the students or?

RM: Er, all of it really.

TM: Um, good question. Er, Cincinnati was the place, to my recollection, that they decided to do it because one of the other leaders, Deb Amend, I don't know if you've spoken to her, um, her family was based there; they had just connections at local colleges and universities where they could have space and dormitories and things like that for the students. So, I think it would just take, I've, I've even been contacted since that organisation has sort of, um, I'm not on the Board anymore; I'm not exactly sure where they're at in terms of they're not doing the camp. But, um, in order for it to be successful, I think, I think it would take some, some manoeuvring. I think probably, probably a, a major city or close-by to one would be, a, a good start. Um, I actually looked at maybe starting something here in Nashville. One of the things that I think would be challenging is just, er, well, just I think there's a, there's a number of things I see as being obstacles for the kids to overcome is like the funding to travel to a place because it's not necessarily going to a place and being, um, centralised amongst a population that already exists in of that place just like working with all different limb difference people in Cincinnati, you know, it requires travel for people from all over to get there and then they have to stay and in that case, they have a parent that stays with them, so that's vacation time away from work and family and other, other obligations. So, there's sort of this, er, there's a, again not impossible because I see it work in other areas especially sports camps. um, but, with music, there aren't that many; I can't really think of any actually that are, er, that have been extremely successful for a long time.

RM: Um, sure, because I was, um, thinking possibly, well again with things, er, like video lessons would allow them not to have to travel that far but then you've got the problem of if you need to be hands-on with, er, placing a certain prosthetic, then you don't have that, things like that.

TM: Exactly. That's been one of the things that I've run into is, er, I have, I have taught many private lessons in my life; now I do more, er, because I tour so much it's hard to keep a regular student schedule. But that is the really challenging thing is just to, you know, is just when internet, internet connections are in and out, you explained that about Skype, you know, I think in one of your emails that, like that something as simple as like that can make it a little bit tough. It's hard sometimes, as a teacher, like to play along with the students, um, or, like you said, adjust something just like really quick; just like a little, you know, um, just move of the wrist or, you know, just put your shoulder here instead of here; that, you know, it takes a special time and consideration to explain versus just to show for a moment. Um, but that's something that I, I've been thinking a lot about is trying to create more videos that maybe speak to those little tweaks that are, that I see the most, at least; start there and keep going.

RM: Yeah, sure, yeah. Okay, um, I'll just move on now to more, er, collaboration stuff. Um, are there any other organisations that you've collaborated with, um, that have helped, er, musicians and non-musicians with, um, limb differences?

TM: Many. Er, I've worked with quite a few. Um, do you want me just to list them or kind of?

RM: Yeah, yeah. Maybe just briefly say how you worked with them.

TM: Okay. So, one of the first ones I was connected with, even before Lucky Fin, was called Hands Down. It's a support group based in the Dallas, Fort Worth area of Texas. Um, they have a great network there because they have an amazing hospital there called Scottish Right Hospital for Children, which provides, er, free prosthetics, if I recall; at least at the time, they were free, for, for children. So, it's a, definitely a, they were also a very well-connected network of families. Er, got together with some regularity and, er, they had a Facebook group that was pretty active and things. Um, it's under newer leadership now but I still see those families with some frequency when I travel through Texas. Um, there's Shriners Hospitals, um, around the United States. I've done two events with the one in Portland, Oregon. Um, where I've spoken to, and met with, families. And what's really interest about that one is that people will travel from 5, 6, and even 7 hours away for, you know, an afternoon concert and meet-and-greet; um, they're just very hungry for the connection and just the opportunity to meet other families. Um, so, that's been really interesting. There's another one called Hands to Love, um, that's based in Florida. I've only, I've done one camp there. It was specifically for, er, it's a very outdoor camp that, er, families are, er, able to come. But they had a music, I, I did music with, with the kids there. They also, there's another one called, um, Helping Hands [Yeah]. which is based,

you've, you've heard of that one? [I've heard of that one, yeah, yeah]. Okay. Um, that one's based in the, er, North East, er, Boston area specifically. And then they have a, have sort of a branch or a wing that's now out in Los Angeles as well but I'm, that one's not as frequently, um, it's not as organised I would say. Um, and then, let's see. There's maybe one or two more I can think of off-hand. Um, I think that's a pretty good list. Oh, Camp Winning Hands?, er, which is based out of the San Francisco, Oakland, um, Bay area in California. They have a camp that they do every Summer for kids who have hand and hand differences and limb differences. Um, and that's, that's really, that's a sleep, that's a sleepover camp; it's a really kind of, the kids get a chance to do rock wall climbing and, you know, nature hikes and things like that and then they're also just building community with other people who have similar differences.

RM: Sure. Okay, thank you, yeah. [Yeah]. Yeah, that was pretty extensive, so, thank you. Um, I was going to ask, um, for your process of, of playing guitar, was there any organisations or people in particular who helped you, er, to allow you to get to where you wanted to be as a guitar player?

TM: Not within the hand community specifically. Um, I would just say more within the music community. Um, so, just other players who were encouraging and, um, I, even when I went to the, the thing was that like, I said before that I had never seen somebody play guitar with one hand before. So, when I got this idea in my mind and brought it to my parents, they were asking me a lot of questions about it. And like, er, you know, first of all, weren't able to buy me an instrument right off, right, just because I asked for one. And, um, and then I went to the guitar teacher in my community and he said that's really cool that you want to learn to play but I don't feel qualified to teach you, um, so you might be on your own. And I, it didn't make me angry or anything, I just kind of felt like okay, that figures because I don't, I've never seen it before either. Um, so I, I learned primarily from books and just from watching other players play and, er, being in bands and, um, just being excited about music.

RM: Sure, okay, yeah. Thank you. Um, so, er, you've done everything very well. I'll just move on to, to my last question now. The whole ,er, PhD process now is I'm trying to pitch an idea for an online database. So, for, er, certain repertoire, technique advice, um, different prosthetics and instruments made being potentially mass-produced. Um, so, something like, like your video, um, of how you make your cast being available to a huge number of people. Um, would you advocate for a project like this in the future?

TM: Yes, absolutely. I'd help you with it too, if there's anything I can contribute or, um, you know, if you want to be in touch in the future about how that would look specifically, I'd be happy to be a resource.

RM: Okay, excellent. Thank you. Um, that's everything I wanted to cover, so, I just wanted to say thank you for your time, Tony, and enjoy the rest of your day and, er, what will happen is I've still got to write up the thesis. Um, so in about six months, possibly a year, depending how long it takes, I'll, er, email you some of the material from this interview that I may use in the thesis. And just, um, you can look through and say yes I'm okay with that to be used or if there is something you want me to tweak, um, I can do that or if you

just, um, if there's something that you want left out completely, er, you can let me know when I send the email.

TM: Sure. That sounds great. Um, I, I just have one, one question for you.

RM: Sure, yeah.

TM: As you've been talking to different resources and putting your information together and research, have you found anybody who's had different perspectives on the idea of mass production of a, in terms of what they've seen, um, that has been useful?

RM: Um, yeah. I think, I think that the problem you were talking about with it's very individualised, um, because all, all the differences are very different. I just think with something, they seem to like the idea of the database because at least then, people have a, er, it's almost a stepping stone for them, that they have something in place, they can be, that can inspire them to build whatever they need to build or, um, allow them to play whatever they want to play, if they're a musician. So, I think, through it, they may potentially lead to mass production. I'm talking in the UK, there's the One-Handed, er, Musical Instrument Trust, er, that's where I met, er, Jen because it was a meeting of people, different organisations looking to build prosthetics for one-handed players of any instrument. Um, and talking to people there, it just seems, you know, these, these people are doing good things but are not talking to each other. So, if we could get that network across of putting it all in one place and then, because you've got the people who prosthetics there; you've got the musicians there; all under one roof, then I think that would help. I think people see that as a way of potentially getting to mass-production. Um, and some of the musicians, I've talked to have said, they've used very expensive materials to begin with and then, er, at the end of the process they've said if I knew then what I know now, it would have cost a, you know, rather than \$4,000, it would have cost \$1,000. So, I'm thinking, if you can save that money at the beginning, then that's a lot of people that can help, you know, for example, say that's four musicians who would be helped right there. So, I just think it's all conversations leading towards it but it, obviously, a long path but I think it's got potential. There's a lot of people who think it's a good idea. [Definitely]. So, yeah.

TM: I love it. Well, I'm excited about it. I'm really grateful that you contacted me, I appreciated your, your correspondence and your kind remarks at the beginning of our, our thread of emails. And I'm really eager for your project and happy to be a resource, as I mentioned as you, er, move forward.

RM: Thank you very much. Yeah and thank you for being so co-operative because these interviews take a lot of time to get someone together or they cancel at the last minute. So, um, yeah. Just want to say good luck with everything that you're doing and I'll contact you in around six months to a year with hopefully, some of your material in the thesis.

TM: Thank you Robbie. It's really good to get to know you this morning – or evening for you [Laughs].

RM: Yeah, yeah. It's late afternoon for me but yeah.

TM: [Laughs]. Yeah, okay.

RM: Thank you very much and enjoy the rest of your day.

TM: Alright, you too. Take care.

RM: Thank you, you too. Thank you, bye bye.

TM: Bye.

Terminates at 25:34

Appendix 10

Commences at 02:29

DS: Hey, Robbie.

RM: Hi, David. Hi.

DS: Hold on one sec. Let me if I can...

RM: No worries.

DS: How's it going?

RM: Yeah, not bad, thanks. How are you?

DS: Pretty good, thanks.

RM: Good, good. Excellent. Um, if you're ready to start, I'll, um go straight on to the interview. If that's okay.

DS: Sure, sure.

RM: Okay, great. Um, so I'll just start with a bit of background, uh, of the organisation. Um, I know that Can-do Musos is a global voice for disabled musicians. So, I just wanted to know, what are the main policies of the organisation for achieving this?

DS: The main policies?

RM: Yeah, uh.

DS: Well, we. Well, one of the things we started, um, we started seven years ago. And we wanted to make, wanted to be a vision for helping all kinds of musicians with various types of challenges and disabilities. We felt that there was nobody doing that. We'd all, we'd all felt that we had been overlooked at one point or another because of our disability. And so, then we thought: what could we do that would give musicians with challenges a voice? So, we came up with Can-do Musos. Um, the story is we went to Dom Famularo. He's a great drummer and, um, teacher. He travels around the world giving inspiring, um, drum clinics and speeches. So, so, a bunch of us were; I live in, I'm from New York City but I live in Connecticut now. So, so, Andrew Hewitt, who was one of the other founders from Australia. Um, was in town on a grant that, that he was from Australia, one of the Australian, uh, uh, government organisations. And, uh, so, Dom, Dom Famularo, Dom [laughs] - that's what everybody calls him, just Dom. Uh, uh, Dom said: 'why don't you come down to my studio?' Uh, Mike Mignogia's going to be here, who I know from, from the drum camps I used to go to. And, uh, Mike has cerebral palsy and then Andrew was going to, um, be in town from Australia. So, that's when we got together and we said, you know, Andrew was just supposed to get a drum lesson from

Dom. [Right.] But he said, you know, I think we have something bigger here. We just need something that would empower people. Um, and we came up with, you know, Can-do; having a can-do attitude is the first step and being at [your] best. And Muso is somebody that, um, is very passionate about music. It's more of a phrase that's used in Europe and Australia. Um, so we sort of matched them together and came up with our, our unique vision. Um, we wanted to be, we wanted to have a unique name. We didn't want to be, you know, so and so coalition for so and so. Um, we wanted to sort of just try to stand out as far as a name goes. So, so, Andrew Hewitt, uh, who did, who still does, uh, he does, uh, what's the [clue?] he does HTML and does website. When he got back to Australia, he started to work on the website, put it together, we started to get more and more, um, members and as of today, I believe we're up to 140+ members, [Yeah.] from 35 countries. So, so, we, we, we just tried to, to build it as best we can and it's happened, you know, a lot of word-of-mouth, people do searches saying: oh, I never, you know, I never, I never saw any organisation like this before, can I be part of it? Sure. And it's, you know, it's, it's a free site so we just make the page, um, and we're a registered 501c3 non-profit. So, so, uh, we don't take any salaries or anything from it. So, does that answer your question?

RM: Yes, yes, that's very detailed, thank you, yeah.

DS: Okay.

RM: Um, so, I'll move on to, uh, how it's, uh, funded itself. Is it, uh, purely through donations?

DS: Yes, through donations, um, we have, um, I have sort of, uh, in roads to, uh, my dad's an investment banker. [Right.] So, and so I, I sort of know that business a little bit because it's sort of in my blood. So, so, I've been able to reach out to people that are investors and they've contributed and then we've had some really nice people that, that Dom and myself know at, at, who, who are, um, he's involved with one of the organisations called The Sessions. They did, they're also a 501c3. Um, and they do events and, and um, events and performances that help people get into the business and, and they have, um, um, interviews with people, um, they have the sessions, which is [a] very popular [interview?] show. And then Dom actually hosts and that's on, um, on YouTube. [Right.] So, you know, talking about how to get into the business and stuff like that, um, and, what, what was your original, original question?

RM: Um, that was basically it. How the, um, how you got the funds, how you get funds - is it just through donations?

DS: So, yeah. So, the person who runs, uh, uh, the person who runs, uh, The Sessions, the person, she's a great photographer and philanthropist named Jules Follett(?) (LINK TO DAN CARO) And she did, she did a, a coffee table drum book back in, I believe it got put out in 2010. And, basically, I had gone to this drum camp, amazing drum camp called COSA(?) And that's where I initially met Dom in 2002. And, you know, I started to study with him, I met all my, you know, drumming idols and Bugle Chancellor(?), who played on Billie Jean; Art Perdy (?), who played on all the Steely Dan records, I mean, and began to study with these people. Um, you know, all, just, just any, anybody you could name in any

genre of music was there. Um, so, D'liberty Devito(?) too, one of my idols from, uh, he played with, uh, Billy Joel (for 30?). So, that summer I saw him, I believe it was 2007 or 8 and, so I was in the village walking around one day, going to Guitar Center and I bump into him. [Yeah.] And he goes: Hey, how you doing? You know, and it's very sort of, uh, it is very sort of nice, uh, friendly, in a (unique?) sort of way. He goes: you still play drums? I said: you bet I do. [Laughs.] And he was walking around with Jules, who was doing this book, um, for, for drummers. So, he said: do you want to be in this book? I said: sure. So, we, so, we, um, so, we, uh, we went around to the Union Square train station; took professional pictures, you know, I did a bio and sent it to them and, you know, a couple of years later, I was in the book (on one page?) And so, Jules, um, has been a, a great friend and contributor to, to our organisation too.

RM: Yeah, sure. Okay, um, with, um, regards to funds again, um, could you describe some of the ways that the funds you get are, are used and how they, uh, help disabled musicians.

DS: Sure, sure. We've, um, we have, uh, for the last five or six years, five or six years, we've performed at the NAMM show and had a panel on disabled musicians. So, one of the ways that, that, the primary ways we, is we, we fly somebody into California; take care of their hotel room and get them into the show and, you know, they're able to connect with a lot of top people in the music industry. Um, we've been doing that for the last couple of years. Uh, before we, um, and, and we've also flown people in from Venezuela, um, and, and um, we helped Andrew to get here from, um, from Australia, who, who comes in with his wife and (son?)-in-law. So, so that's a huge trip. Um, and since we became, um, a 501c3, only, you know, I think it's a little over, I think it's a little over or a little under two years, you know, we've been under restrictions(?). So, so, he has to raise the money, which he's done. To come out, he's done fundraisers himself. Um, and the money, as far [as], he's had help from the Government too, um, like he did the first time we met. [Yeah.] Uh, so, so, basically, we, and we've also donated money to the people, we've donated to one of our members who's, who's a chronic stutterer, um, in India. [Yeah.] So, uh, we donated money, um, because he said that they're very much a cast system there. So, uh, he comes from a long generation of, of stuttering, of stutterers. So, we were able to, um, wire money to help them, uh, purchase a drum set for their, uh, for their Christian church.

RM: Right, yeah. Yeah, okay. With the, you talked about the NAMM, um, trade shows. Um, have you found that it's really helped disabled musicians, um, being represented there and allowed them to get into the music business?

DS: Say, say it again, I'm sorry.

RM: Um, so, with the NAMM trade shows, do you feel that that's helped, uh, disabled musicians get into the music business? Um, have you seen that, have you seen evidence of that at the shows?

DS: Yes, yes. One of, one of the members who lives out in California. His name is, um, uh, George, um, I'm sorry, Gino Oceaniano(?). And he's a drummer and he actually has the

same disability that I have, which is called anthrogyclosis(?). When he was out with us the first time, we had a commercial, um, uh, director, who's, you know, done movies and commercials, um, did a whole thing on Gino. And that was directly because it was part of, um, it was at the NAMM show and part of a presentation. So, they, they did a whole feature on him that won, that won a number, I think, I think it won awards. Um, so, so, that happened, um, um, trying to think of what else. So, people have gotten, uh, uh, what are they called, endorsement deals from there. I'm trying to think of, of what else. Um, well, one of the things that, that we've almost become, we've also become a, a referral source, almost like a casting agency. A lot of directors have used our website to find people. So, one of the first things we did, we, we helped, um, one of the drummers get an Audi commercial. We flew him out to California, um, and we helped him get a bunch of gigs because people have called us looking for him. And we, we haven't taken a dime, you know. All the money is for them (you know what I mean?). We haven't, we haven't gotten a percentage. Um, and then, one of our proudest moments was we had, I think it, I think it's seven to ten members. Um, we were contacted by the BBC [I think it's Channel 4], um, in 2006 [I think he means 2016]. And they were doing, um, they were doing a, an amazing commercial called "Yes I Can' for the Paralympics. Have you heard of it?

RM: Yeah, I've heard of it. Yeah, yeah.

DS: Yeah. So, so, they were doing a commercial and they flew six, they flew, they flew seven to ten members out on their dime, um, to Abbey Road Studios to perform this great song and production of "Yes I Can". So, and, and people, you know, people are still getting work because of that commercial.

RM: Yeah, yeah. That's good. Okay. Um, so, I'll just move now, uh, to the website in particular, um, because you earlier said that musicians approach, uh, you, but do you, uh, as an organisation approach some say high-profile musicians to say, um, would you be on our website because it might get, uh, work for other people; it might expand the network, I suppose?

DS: Yes we do. One of, one of the most high-profile people we have on our website is an amazing percussionist named, uh, uh, uh, Evelyn Glennie, [Yeah, yeah.] who is profoundly deaf. And, and she's been a great supporter. Um, you know, we talked to their managers and, and, and we, um, we got permission. And she said: sure, I'll, I'll be part of your organisation. Um, we've had other people, we had at our last, uh, at our last NAMM show, um, Leiland Sclar(?), uh, a legendary bass player was there. He's also put out, um, things on, uh, Facebook to help promote us. Um, we're still looking for, we're still trying to get, uh, one year, we, uh, let me take you back to, uh, to, um, to our first year presenting at the show. I had heard stories of, that, uh, Stevie Wonder comes to NAMM and just, you know, tries out all of our, a lot of the instruments. So, so, I was like, I wish we could see him. So, then Sunday arrives of our presentation, we finish, Dom comes in to, uh, and he goes: David, stop everything you're doing and go out there. Um, uh, Stevie Wonder is next door. Go wait for him. So, that's what we'll do. For half an hour, we'll wait for him. Um, he comes out, I introduce myself, you know, I mean, he's a legend for us, you know, an amazing inspiration. And so, we talk to him a bit, um, you know, we know he's very busy. So, we tell him about our organisation and we'd love to have him [on the?]

website. So, hopefully, hopefully, one day we will, um, have him. So, so, that was just an amazing story. Um, so.

RM: Yeah, good. So, I'll move on now to, uh, sort of the individual, uh, biographies of the musicians and the pitches and videos they use. Um, is that entirely up to the musicians', what's on, uh, the website or do you have any input in say, recommend certain things to use or certain, you know, biographies, parts of biographies to use?

DS: Yes. We, um, we tell, we tell them to send what they have, um, and we make recommendations to them as to what to put, if they don't have, uh, you know, uh, uh, a proper biography or video, and we give them all, all kinds of advice on what to put in it. Uh, we said, you know, use this person as a template for what to include. So, so, we'll work with them and, you know, our goal is to, is to make the best, uh, page possible for them.

RM: Yeah, sure. Okay, thank you. Uh, so I'm going to move now, uh, a bit more specifically on to my work, as I'm looking at musicians with absent limbs and digits. Um, is there any specific things you've done for these groups of musicians?

DS: Say it again, I'm sorry.

RM: That's alright. Have you done, has, uh, Can-Do Musos done anything in particular to these groups, group of musicians?

DS: Who are missing limbs or digits?

RM: Yes, yeah.

DS: Um, yes. I mean, it's, um, the inbound we get, you know, we, I mean, we, we don't segment, you know, who gets what work or, or whatever, but, but we, we've had a lot of interest from, you know, drummers and guitar players that play drums or guitar with their feet. [Yeah.] So, so, they've gotten a lot of work from us. [Laughs.]

RM: Yeah, yeah, sure. Um, so, if there was a, say a, a guitarist who uses their feet, um, would Can-do Musos just only give advice or would they actually, uh, find someone who could make say prosthetics or an adapted instrument, uh, maybe based on some of the, someone in a similar position?

DS: Yes, yeah. Somebody who's having trouble, um, adapting and saying how do I do this? We, we refer them to, uh, this musician that plays guitar with his feet or this musician that, that's missing, an, a hand, a musician that has cerebral palsy or arthroprosis(?), like how to hold the stick, you know. I built a device that I use in my left hand to hold the stick. So, I've helped(?) people in that area. So, so, yeah. [Sure.] We(?) give advice on, for people on how to play and adapt their instrument.

RM: Um, yeah, sure. Um, so, moving on to, uh, on to the instruments and prosthetics themselves. Have you found any evidence that these have become cheaper and more

mass-produced over time or do you feel it is still very, uh, personal to a certain musician, based on their needs?

DS: I'm sorry. Can you repeat the question?

RM: Yeah, sure. Um, so, with, uh, adapted instruments and prosthetics, uh, have you found that they've become cheaper and mass-produced or, you know, at least with a few, uh, uh, a bit in bulk, um?

DS: I know what you mean. [Yeah.] Uh, some people have used; there's something called The Trip, The Triplet Glove [Right, yeah.] for people that are having difficulty holding a drumstick. Uh, so I refer, I refer people for that. And that's a mass, that's a mass, mass-produced, um, um, a mass-produced, uh, device that will help the, the musician play. But then, I've also had people where, where they've copied, they've copied my device and had, you know, had their parent(?) make one for them or have given the doctor who made this one for me, I give them their phone number and they, they've made it, you know.

RM: Yeah, sure. Um, and also, uh, moving on from that. With, uh, say specific repertoire for playing guitar with feet, with different toe positions. Um, have you found any sort of say sheet music or anything specific for certain disabilities?

DS: No, I haven't. Uh, I'm not sure, um, I play, I play in a band with Mark Goffeney, plays guitar with feet. And he basically knows all the chords. So, he's not really looking at sheet music. He just knows the chords(?) of his songs or any of the cover songs that we do.

RM: Okay, sure. Uh, so, I was going to move on to a bit more advocacy stuff now. So, um, does Can-do Musos, uh, collaborate, uh, with other musicians or other organisations, um, frequently or, or sponsors on a frequent basis?

DS: As much as we can, yes. [Okay.] Um, we've gotten involved with an organisation in New York called Danny's Music Foundation that helps disabled musicians and, and helps fund, um, um, music lessons for disabled musicians. And so, we've been involved with them for the last, I would say, close to a year now and we, we received an award, um, in March before everything got put(?) down. Um, so, and we had, we had, it was a contest. So, we had basically three, three of our members, three or four of our members perform. That won, that won one of the slots in the contest. So, we work, we work with them and they, uh, some of them had to just submit a video tape or (video?) and others, others did, did, who were located in the US, were able to attend and perform at the event. Um, and we've, we've worked with, um, myself, Mark Goffeney and myself. We were invited to play a festival for disabled musicians or disabled art, the digital, the disabled arts, you know, we ran the gambit(?). Uh, we went to Turkey, um, to play. So, we worked with them and we also got three other members of Can-do Musos to play that festival.

RM: Sure, okay, Um, so I'll just move on to my, um, final question. I've had, uh, an idea for an online database for disabled musicians. So, if one central database was created for

repertoire, technique advice, uh, availability of prosthetics and adapted instruments to help disabled musicians, um, would you advocate for this?

DS: Uh, so, so, what was it? I'm sorry.

RM: That's alright. Um, it's a, so, it's a central database for disabled musicians where it had, uh, a repertoire, technique advice, prosthetics, uh, adapted instruments. Um, would you advocate for something like this?

DS: Sure, absolutely.

RM: Okay, thank you, That's, that's all my questions. So, I just want to say thanks a lot for taking part. Um, so what will happen now is I'll transcribe this. Um, I still have to go through my thesis and do, uh, many parts of it. But I'll send this on to you, um, probably may take a year, um, to do, uh, with the, the certain bits of this interview that I'm going to use. {Right.} And then, um, I'll send it on to you and all you have to do is say, uh: yes, I'm fine with this or if you want something, uh, edited, just let me know what part of it you want edited and I'll change it, or if you want me to leave something out entirely, uh, just say. And you don't need to give a reason why but just let me know which bit you want, uh, taken out.

DS: Okay. So, what's your, what's your, what's your thesis question?

RM: Uh, it's an investigation into, uh, musicians with missing limbs and digits in popular music. So, it's looking at, uh, beginning with, uh, a popular example in music. So, probably the most famous examples and then moving on to, uh, musicianship techniques. So, that's what musicians, the musicians using prosthetics and others not using prosthetics and then others playing adapted instruments or playing, uh, new instruments that try and replicate the, I suppose, conventional instrument. Uh, then I'm looking at organisational and, uh, institutional support. [Right.] And then, my ad, advocacy question at the end is how I'm finishing it with, um, basically is there a demand for it?

DS: Yes, I, I think we're, we're putting the demand out there. [Yeah, sure, yeah.] People are sort of noticing us and noticing that there's some sort of untapped talent out there in the, in the musical world for, that's for people that have disabled, that certain, have disabilities. Um, so, we are, we're, we're thrilled to be a part of it and help people, you know, uh, live their dreams. Uh, because we all, we all, and, you know, just because you've got a disability, doesn't mean you don't aim big. And one of the things we, we, we actually and, and, it's, it's funny; I'll let you go but [That's alright.] but I thought of a funny story. Um, so, when, when, when you're disabled, you always think you're alone. [Yeah.] The only one who has to deal with [it], you know, and through this, I've found five drumming brothers that all have anthromicosis(?) and play drums — very good. And, you know, whereas, whereas, before I would just, and a lot of other musicians, a lot of other musicians with disabilities would say that, I'll just go ahead and say it(?), they just want to blend in. [Yeah, yeah, sure.] Um, you know, you know, they want to hide, you know, they want to hide (in spite of?) and make it that they're(?) quote unquote "normal" but, but what this has done is created, um, um, a camaraderie. [Yeah.] With people working

together, with all types of, and you don't feel, you don't feel so alone. [Laughs.] [Sure.] You feel like somebody knows what you're going through. Um, what things I'm, we met this, um, this girl. She's a teenager(?). She, she actually has a form of arthbicosis(?). And we met her and her dad at this, at the Dania(?) Music Award. [Right.] And, and after her, after it, and after us talking, and, um, he said: you know, what I like, I like about your organisation, um, I like it that you have an attitude where you aim big. It's not, it's not, you know, where, he said it's not like with other, other, other organisations that he's, that he's been maybe involved with or looked at been involved with. They've been like pity parties. [Yeah.] You know, whereas, you ain't gonna get that from us, you know. [Sure.] We want everybody to just do their best, knock 'em dead, and be the best that they can be. [Sure, yeah.] So, and that's what, that's what he liked about our organisation. [Um, absolutely.] Everybody, everybody has their own, has their own, has their own, uh, has their chance to shine.

RM: Sure, yeah, yeah. Yeah, I mean, even in, uh, my own research, I'm finding, um, examples of how, well I suppose, universal adaptions have been made and have just been, uh, overseen, you know, overlooked because it's for "normal" quote unquote people [Right.] just as like an adjustable, uh, piano bench, you know, just so someone's at the right height to push the pedals. And it's just been, uh, accepted because it's needed. Or, you know, a page turner for sheet music, you know, you need someone else there to do it. [Right.] Um, so yeah that's, I'm bringing that into the equation as well, just how it's all, it can be applicable to so many people. And if we find out, uh, more ways that apply to more people, then it becomes cheaper and it becomes more mass-produced and [Right. More mass -produced.] helps everyone out.

DS: Um, and you know it's a, it's a cliché but it's really true in its essence: necessity is the mother of invention. [Um, sure.] Sure, you know, have everybody finding a way to make it work for them, however they need to, you know.

RM: Yeah, yeah, sure. Alright, well, thanks a lot for, uh, taking part as I said. And, um, yeah, I, when I, uh, get round to doing all the interviews and putting in my thesis, I'll send that email on to you. [Okay.] Um, but yeah, once again, thanks and I'll email you hopefully not in the too distant future [Laughs.]

DS: Okay, sounds good, Robbie.

RM: Okay, great, thank you. Cheers David.

DS: Bye bye.

RM: See ya, bye.

DS: Bye bye.

Ends at 38:00.

Appendix 11

Interview starts at 03:50

RM: Hello?

GD: Hi Robbie.

RM: Hi George, how are you?

GD: Hello. Good, how are you doing?

RM: Yeah, not bad, thanks. Good. Yeah, um, so, just before we start, are there any questions you have or are you all okay?

GD: Um, did you, did you get my, the Consent Form?

RM: Yes, I did. Yeah, thank you. Yeah.

GD: Oh great, okay.

RM: I've, um, yeah, I didn't have time to, er, check my, well, properly check my emails this morning, um.

GD: Oh, great.

RM: But yeah, I did see it. So, yeah, thank you for doing that.

GD: Okay, wonderful. Um, um, well actually, just, just, so I know to, er, what timeframe are you thinking the, the interview will take?

RM: Er, roughly around 30 minutes, um.

GD: Okay.

RM: A proper, at most it will probably be an hour, but.

GD: Yeah, sound, sounds good. I want, wanted to check, er, er, charge my phone up, so.

RM: [Laughs] Okay.

GD: Um, I'll, I'll let you know if I need to grab my it, but, but I should be fine.

RM: Okay, great.

GD: Um, no, but, but I'm good, good, whenever. Oh, actually I do have one more question too.

RM: Sure.

GD: Um, will, will it be possible to, to, get a copy of, of, er, what you, what you, er, write up?

RM: Er, yeah. So, I was, er, actually at the end, I usually say, um, what I'm going to do, but I might as well tell you now. Um, so after this interview, I'll, er, be writing up my thesis and then any bits I use from this interview, er, in the thesis, I'll send on to you, um, once it's all done. Um, and then, that will probably be 6 to 12 months down the line. And then, er, if you're okay with all of it, you can say, yes that's fine, or, er, if there's a certain bit you want me to edit, I can do that as well, or, if there's something you want me to take out entirely, um, you can do that as well. Just, you don't need to give a reason, just tell me what part you want me to get rid of.

GD: Sounds good.

RM: Um, if you want the transcription of the interview, um, I can do that sooner than 6 months but I don't know if you'll want all of it, because there'll be sort of ums and ahs and.

GD: No, no, no, that's, that's okay. I, I think I was thinking more of once, I mean, er, it would be nice to able to, er, to see what you're thinking, but, but, but, er, especially once you're all, once you're all done and it's all written up, and, and I'd love to have a copy of, er, of, of, you know, what you come up with at, at the end of it too.

RM: Oh, yeah sure. I'll, um, once I've, er, done the PhD, I'll, er, I'm sure I'll be able to do that. I'm sure my, er, supervisors will...

GD: That's awesome.

RM: Yeah, I'll, I'll keep you posted throughout, um.

GD: Awesome.

RM: Um, so, yeah.

GD: That sounds great, I, I appreciate that.

RM: No worries, no worries.

GD: Yeah.

RM: Um, so, if you're ready to start, um,

GD: Sure.

RM: Do you mind just stating your name and giving a brief description of who you are and what you do?

GD: Yes, er, so my name's George Dennehy. I'm 26 years old and I live in US. Er, I was, I was born in Romania and, er, I was born without arms. Er, I was adopted at the age of 1 and a half and er, I, 1 grew up, er, just learning how to live life without arms and using my feet and just using what I have. Um, and, er, from an early age, I developed, er, just a, a, love and passion for, for music er, and, and really a natural ear for it too. So, my parents, er, helped cultivate that, er, really encouraged me and pushed me to, to just learn music and take lessons and, and, er, learn how to, er, play instruments, and, and, play instruments, er, my own way with my feet and my toes and just a lot of work and a lot of, um, a lot of trial and error, um, figuring out, how, how I could do that. And, and, and, er, er, but here I am, you know, twenty some years, years later and, and, right now, I, I do music full-time. Er, and I, and I travel and speak and share my story and, and hopefully motivate people and encourage people, er, to chase their own dreams and, and not let their own challenges, er, hold them back from, from doing what they want to do. Um, So, that's a little, little bit about me and, and kind of an overview of it.

RM: Sure. Okay, thank you. [Yeah]. Um, just quickly on that point, with you saying that you do music full-time, um, in what capacity is that?

GD: Um, so I've, er, I, I travel, er, full-time and I, I do concerts and events and, er, kind of keynote presentations to, to schools – I do assemblies and, er, er, you know, non-profit events and fundraisers and, er, churches and, and really all, all over. Uh, the list is, well it couldn't be endless. [No – Laughs]. And I, and I, so I do a mixture of, of playing music, playing songs I've written – I write songs too; I have an album out. Um, and, er, and I do a mixture of that and, er, speaking and just, and sharing, sharing my story; my experiences; talking about challenges and I've, I've been doing that full-time just as my career, um, for, for the last eight, eight or so years.

RM: Um, okay, thank you, yeah. Um, so from here I'll, I'll talk more about the media stuff actually at the moment. Um, so, I've seen a lot of documentaries and videos on your channel and, er, various news segments where it combines you playing musical instruments and doing everyday tasks. Um, do you feel that sort of, er, display of what you do helps people understand how you use your feet as hands and how that translates from day-to-day life into your instrument playing?

GD: Um, yeah I, I think so and I certainly hope so. I, I hope that, er, through just maybe little videos here and there and, and, and, er, things people may be able to see, that, that they can see that I, you know, have, have figured out how to do mean virtually everything that everybody else does. I just, I just do it differently – I just do it with my, with my, with my feet. And, um, you know, I'm always open for, for a challenge and how, um, you know, I, I, I love to, love to live, you know, I love life and I love music. And I think it's, it's always been, um, you know, that, when I was younger, there was that struggle of if I, if I thought was good enough or if I was capable or if, if I saw my disability as a hindrance. Um, but, you know, now kind of working, having worked through that, and, and getting through that, um, you know, I, I realise that, that I'm fully capable. Um, and it starts in my mind, you know, it starts if I'm, I'm mentally capable and mentally ready to, to face the challenge. [Sure]. And I,

I, I do hope people can see that when they, when they come across my pages or my website or videos or however they might, might interact with me.

RM: Sure, okay. Um, so and obviously another event that comes up from this, um, which seems to be catalyst was you, er, performing with the Goo Goo Dolls and opening for them. Um, and on your website, it's described as, er, your career taking off ever since. Um, could you perhaps describe some of the ways that your career has taken off since then?

GD: Um, yeah, you know, I think. Well, I mean, I, I should say first, first and foremost that, that opportunity to, to perform, er, with the Goo Goo Dolls- a group that I've, that I've always loved since I was in middle school and high school and I, I've just always loved that kind of music and really look up to them. Um, I, I think that was my really pivotal moment for me, um, er, definitely with my career but also just, er, within, with my own self too and, and the way that I see myself and how comfortable I am with myself. Um, it was a really big crowd, it was really nerve-wracking and I was really, I was just really nervous, you know. And I was real young – I was 18, I had just graduated high school. And, um, but to, to experience that excitement and, and that love from that crowd, um, when I, when I was out on stage and, you know, I was kind of, it was kind of the first time I really showed myself to the world, you know. And, and put myself out there on this, this stage and, and with, my, my feet and my, I was, my legs and I'm playing guitar with my feet. And not that many people at one point had seen me doing that. And, um, so that was really like the first time, I had, I had just done that and I was playing the song "Iris", which, which, I can't think about a more perfect song for that moment. Um, so, I think the, the mixture of that and, and just the practical playing on a big stage like that, with that kind of group, and, and just the snowball effect that that had with, with different, um, just local newspapers and news stations and then, and then, er, you know, with the news stations with my city and then national news stations and things like that, you know. It, it was kind of like a snowball effect. And, um, that's just kind of turned into a lot of, kind of turned into what I do now, which is, um, is just carrying that on. And I think, I think having that experience and, and really feeling comfortable after that and seeing that, that, you know, people, I think people inherently, um, want to see their fellow human overcoming challenges.

RM: Sure, sure. Thank you, yeah. Um, so, from here, the, the next part of the interview is going to be about, um, to do with technique and your instrument playing. [Yeah.] Um, so shall I start with the piano stuff? So, um, on your bio, it says that it's basic piano, um, why would you say it's basic?

GD: Um, I, I would say it's basic because I've, I've never actually taken piano lessons and, and I haven't really, er, put in the, I guess I would say I haven't really, er, put in, the, the effort enough to, to really hone in and, and develop my piano playing. Um, I don't really own a piano, so all the piano I do play is when I visit, I go see my parents, which is, you know, pretty frequently. Um, so, I, I think, I mean me playing piano is, is purely just based off of my knowledge of music and just kind of knowing how notes work and chords work and, and I can, I can get by, you know, I can, I can play some songs; I can, I can play melodies and I can write songs on the piano too. [Yeah.] But if you put in, if you put a, you know, a, a concerto – sheet music in front of me, on the piano, there's, there's no way. [Laughs.].

RM: [Laughs.] Sure, okay. So, I'll move on now to, um, or, when you were, er, playing the cello obviously, er, would be your first instrument and the struggles with that. Um, could you possibly talk through some of the methods you went through, um, in order to play the cello successfully, um, and possibly give an idea of how long that process took before you were comfortable and maybe any particular difficult techniques that you encountered?

GD: Yeah, you know, I, I, playing, playing the cello and learning how to play the cello, er, is, is, is really what started me playing music – that was the first instrument I had ever learned and, um, and it was, it was a lot of, it was a lot of work and it was, it was really, really challenging. Um, you know, cos, cos using my feet for just daily things, um, you know, that, I think similar to how people use their hands for daily things and learn how to use their hands as a child, er, those things just kind of came naturally, you know. And just kind of the way of life and, and the way, you know, your body and mind develops, I think, er, I was just able to just kind of pick things up and, and, and use my feet. But learning an instrument, you know, you, you have, you learn it and you have to practice and you have to, you know, teach your muscles and muscle memory and, you know, all of that and, and I was doing that with my toes. And, you know, thankfully and, and really miraculously, I, I had the most amazing, er, teacher. And, er, she was a lady that, er, er, we, we, our family knew, er, just through our town and our, our, you know, small church and things like that. And, er, she, she taught a lot of just, er, kids – she kind of had her own, er, teaching academy thing that she did and, er, she agreed, er, to teach me too, er, knowing that it'd be a challenge. And, er, she, she took it upon herself to learn how to play the cello with her feet before she taught me. [Right, right.]. Um, she, you know, when, when my parents approached her about teaching me cello, er, you know, I can't imagine just a whole load of thoughts and, and questions and maybe even doubts that, that went through her mind, er, with that. But, you know, she was persistent and she, she's a person who believes, you know, and, er, so, she, she wanted to teach herself first and she realised that it, it could be done, with the cello laying kind of on, on the floor and holding the bow with one foot and doing the notes with the other foot. And, um, so then teaching me a, a lot of that was us kind of working together to figure out how different things might work best, I, I guess, I would say. Um, and, and honestly, er, one thing I can clearly remember – I, I, I was really young, er, er, I was seven at this point. And, um, but one thing I can clearly remember is how important it was, er, for me to be able to move each toe by itself. [Yeah, yeah.]. Um, and have that dexterity to do that. So, I mean honestly some, some Thursdays, I remember, it was on Thursdays when I had lessons, some Thursdays, we spend the whole hour not even playing the cello. She would just hold my, my toes down on the ground and tell me to just lift all toes except one, uh, on my one foot. And she would tell me to just lift the one toe that's not being held down and I would just do that over and over again, it's like, it was just like an exercise. [Yeah.] And, and I would do that over and over again for weeks and however long until I could just do that myself and without her holding them down. And that translated, you know, really, really well into my playing the cello and, and having the dexterity to play the notes and move my toes fast if I need to and, and, um, that's, that's just one thing I can, I can vividly remember. [um, yeah, sure.]. Um, so, so, yeah.

RM: Fair enough. Um, how long do you say it took before you reached a point where you were comfortable with it?

GD: Yeah, that's a, a good question too. I, I, I think it maybe took [long pause] two years, I would say [Okay, yeah] until I felt really, really, just comfortable and I felt like I really took, a, a step into just going from like being a, a student and learning to actually kinda holding my own and being somewhat decent at it. [Um, sure.]. Um, yeah. So, I mean two years of, of lots of practice and, and, you know, a lesson every week and, and, um, recitals and, and, you know, we'd have our, we'd have our lessons individually but then she also had a, the program where, you know, all the kids who took lessons from her were also, she'd also do like a group orchestra. [Yeah, yeah.]. And we did that too. And that helped me kind of play in a group setting and take on some lead, leadership roles too. Because she, er, she, er, would kind of delegate a lot of things to me, er, to help my, my section, the, the cello section, er, even at a young age and I was, was kind of, I had other kids who were much older than me. I mean, I was 9 and, you know, they were maybe 12 and 13.

RM: Yeah, yeah. [Yeah.]. Yeah, um, by any chance is the person you're referring to, er, Jennifer Petry

GD: Yes, she is.

RM: Yeah, I've interviewed her already, um. [Oh, really]. Yeah, and she, she was saying about how, um, she used your methods as a sort of basis to teach others. [Wow.] Um, so that it was interesting definitely hearing about what you were saying about, er, collaborating almost, coming up with the methods.

GD: That's amazing. [Laughs.] That, that's so cool. Yeah, she's, she's, she's, what she, she's truly one-of-a-kind. And, and I love, I love that she, you know, adopted so many children in, in, in many, and a couple of children just like me. And it's cool to see her, her kids learning, you know, she, she used a lot of what she taught me to teach her kids and her kids are way better than me now at, at, at the cello - I don't know if they play guitar. But I'll give, I'll give them the credit where credit's due, you know, they can, they can definitely beat me in a, in a cello duel. [Laughs.]

RM: Yeah, fair enough. Um, so, also she's got the, er, Adaptive Music Camp in the Cincinnati, er, Project. Um, so I was wondering if she ever approached you, er, with teaching any of their students about your methods or perhaps when she was talking about it, she just said she used your methods as a basis to teach others?

GD: Yeah, I she, I haven't, I haven't worked any, worked, worked with her at all for, for what she does. [No, that's fine]. Um, so, so, it's, it's cool to hear that she, she definitely uses, you know, the same methods that she used, er, to help me to others too. I think, I think that's really, really neat.

RM: Yeah, yeah, good, okay. Um, so, I was gonna move, er, from the cello now to the bass guitar and just, er, trying to understand how that was transitioning because obviously you've got a fretless instrument to a fretted instrument, um, and you're strumming, well, or playing with a pick rather than playing with a bow, um, so, perhaps you could just, er, explain how that transition was for you?

GD: Yeah, you know, transitioning from the cello to, to bass guitar. So, yeah, I, I, I learned the bass guitar before I, I started teaching myself the guitar. [Yeah.] And, and, er, there's probably about a year or so I put in bass before I went to, to a guitar as well. But, you know, so, so, going from cello to the bass, it, was, was, was different in, in a lot of ways. As, as you mentioned, you know, there's no frets on a cello to frets on a bass and, and I've been so used to holding a bow on a cello and here I am without a bow and I'm using, I'm either using a pick. But, you know, thankfully, learning the cello, um, well, well, there are a lot of parts where I'm plucking(?) too when. And especially in an orchestra where you're plucking instead of using a bow, and, and plucking is, is basically finger picking, um, on a bass or a guitar, kind of, at, at least for me, it was, it was very similar. [Yeah, sure, yeah]. Um, so, when I learned to play bass, it was, it was, I just kind of told myself: "okay, I'm, I'm basically just, I'm, I'm plucking this instrument". Um, but then using, using the, using the, using the frets and the notes – um, the strings on a bass are different than the strings on a cello – so, you know, that, that took a little bit of, but there's still four strings, so, it kinda looks similar, but the notes are all different. So, so, I definitely had to make that, you know, correlation and, and transition into, you know, okay, so, now instead of C G D and A on a cello, I'm doing E A D G on a bass and, you know, all the changes. So, er, um, thankfully, I, I, I had, I had a really great, er, teacher for bass too. And, you know, he, he didn't, he helped me, er, learn kind of just the bass itself and the music and the music theory behind playing bass. Um, and, but thankfully, you know, I, I'll, I'll definitely say that, er, physically learning, er, playing the bass, er, was, was kind of an easy, easy transition, er, because it is, it is very similar to, to a cello. Um, you know, other than just, other than just frets which kind of make it easier to be honest. [Um, yeah]. Yeah. So, yeah.

RM: Good. Was there any, er, difficulty changing from bass guitar to guitar then?

GD: Er, yeah. I would, I would say going from, er, cello / bass guitar, er, but yeah, bass guitar to, to guitar was, was much different because, um, I think that, that took probably the most - well, I don't want to say the most time - um, it took a lot of effort because I, I'm, I'm learning how to hold a pick and I've never really held a pick before and there's six strings and you're not always just playing one note at a time; you're strumming chords and you're doing down strums and up strums and then you're doing different rhythm with it - um, that took, that took a lot of work. And, and it was, it was really challenging because it was so different and, I, I didn't know if I'd be able to do the chords or if I'd be able to, you know, strum the whole guitar or how do I keep the guitar from shaking when I'm strumming it? stuff like that. How do I, how do I push down on the guitar, er, and play the chords but the, the, the, the tuners [tuning pegs] on the guitar – how do they not hit the floor and, and get the guitar out of tune? Um, yeah, a lot of, a lot of just kinda things to, to figure out and, and work around, um, and it, and it was, I would say definitely a, a difficult transition. And, and I got, I, I, I got frustrated a lot doing it because I, it was so different that I, I just, there were times where I thought, you know, maybe, maybe someone like me can't really play a guitar; I mean that, that's, there's so much going on with that - maybe I just need to stick to kinda, I don't, I don't want to say the, the easier instruments but kind of the more simple, as far as an instrument is concerned, for, for the instrument itself, er, whether it's four strings, maybe I just need to stick to a four-string instrument and play one note at a time, you know, maybe that, maybe that's all I can do. Um, but, you know, I, I had that mentality and that

discipline to, to keep figuring it out and, and, um, and figure out and, and here I am today, er, you know, still, still learning and still practising and still teaching myself.

RM: Um, yeah, great. Um, so, with, er, the cello, bass, and guitar, did you find, er, when you were positioning it on the floor that you had to change positions slightly for each or did you find that there was one set position that worked, then you stuck with it?

GD: So, they, they're all, they're all facing, each instrument's facing the same way. And, and that, that's really, it, it was cool because that was one of the first things I remember doing with, with Mrs. Petry was she just told me, um: alright, put the, put the cello how, how you want it, really. And I, I, I don't know if you've ever, er, skateboarded or anything – I used to skateboard too for fun; it's kind of similar like when you get on the skateboard for a first time, you're either, you either step on it, you know, regular or, or goofy meaning like you have you're right foot forward or, or, you know, you might be, I don't know the other terms but, you might be riding on, on it from your, you might be closer to the front of the skateboard than the back, some people do that. Um, and, and that was kind of just like, what's your preference, you know? Here's your, here's your tool – what, what's comfortable? So, that's kind of what Mrs. Petry did where, with the cello and, and I just found, even though I'm right-footed, you know, I, I, I'm very much right dominant. Um, so, I, I write, you know, with pens and pen, pens and pencils with my right foot; I eat, hold a fork with my right foot; drive, I hold, I drive my car with my right foot at least the wheel. Um, but with, with an instrument, I was just more comfortable for me to, to use the bow with my left foot and, and I strum with my left foot, and I, I do all the notes with my right foot. Um, so, so, each, each instrument's facing the same way, er, with the cello, I don't know if Mrs. Petry talked to you about, er, the custom-made stands? [Briefly, yeah, er]. Yeah. [Not, yeah, yeah]. Um, yeah, so, those, those custom-made stands, I have the, the wood knobs and they hold the instrument up and tilt it a little bit for, for us, er, individuals to, to sit on a stool and play the instrument with our feet, um - that's how the, the cello sits. Er, my guitar, you know, does sit, sit on the floor but then I, I put a mat under it and I have a custom-made Styrofoam thing that, that attaches to the top of the guitar so the, the tuners don't get out of tune, um, so, it can sit up just a little bit. And, er, when I was playing bass, I put just like a, a, a, a wooden block basically, like a, but it, it, the wooden block was matted with, with tape and stuff, so it was soft. And I put it under the neck of the bass, because a bass is flat, you know; a guitar is rounded but a bass it flat, so, I put the, put it on, put it under the neck of the bass, so, the bass would just sit just a little bit up, so it wouldn't get out of tune. Um, so, so yeah, so each, each instrument faces the same way, um, but I kind of just use different things with each, well, with each instrument to make it, er, um, just doable and, and more playable.

RM: Sure, um, so, with those materials, er, how many materials did you go through before you found the one that worked?

GD: Um, you know, I, I, I didn't actually go through many. And, and I'm so thankful, er, throughout the course of my life, I, I just had, I've had so many people, um, who have come alongside and, and just helped and, and saw a need and helped. And a lot of these people, er, where, you know, people like Mrs. Petry and then other people in, in, in like my, my church bands that I was a part of. Um, when I started learning to play bass, I mean I'm sure I

was in this band and I'm sure it was annoying for, for them to be playing, you know, on a Sunday morning or a practice and they hear my, my, my bass go out of tune all the time. So, I'm playing wrong notes because my, my bass is out of tune. Um, and, and that's probably, that was probably, you know, frustrating. So, I mean I know, I know they wanted they, of course, wanted to help tune. So, um, one, one of the band members kind of put together this wooden block and said: "here, try this". Um, for a little bit before, they, they helped, er, er, I got that wooden block, I would just use my shoe. [Right, yeah]. So, I would, I would just take like my shoe and put it under my, my bass and, um, hold it up. Um, so, I, I actually, I thankfully didn't really go through many materials before, you know, using what I use now. Um, the, those first things that the, the people offered to help me with, er, I still use today.

RM: Yeah, that's good, yeah. Um, were there any, er, modifications you had to make to the, the picks or the bows at all that you used?

GD: Um, yeah. So, so, the, the bow for the cello – this was a great idea by, by Mrs. Petry. Um, it's, it's kind of, it, it's a little difficult to be able to hold a bow, er, from, from the top looking down, you know. [Yeah, yeah]. Um, so, her, her idea was to take, er, the frog, the frog of the bow, which, er, you know, is, is that part on the bottom that kinda attaches to the, to the, to the, er, horsehair. Um, she took a, a, a frog and, and put it upside down on the top of the bow, kind of in the same adjacent spot that, er, that, er, it is at the bottom. And then kind of lined, wrapped that up in tape and made it kind of soft and cushiony. And I could, you know, hold, hold that part of the, the frog with my big toe and my next toe – I call it my fourth toe. So, when I, when I'm talking about my, um, toes and, and music, I, I kind of start from my pinky [little] and that's 1, 2, 3, 4, 5. Or, or 1, 2, 3, 4, big toe. [Yeah, I've got you, yeah]. Um, so, then I'm holding the, the bow, er, er, with the frog, er, with my, with my big toe and fourth, fourth toe. Um, and, that, that's, that was really, that was really helpful because then I could hold it and then apply pressure now on, onto play the cello and, and that was, that was really, really helpful. And it's, and for bass and guitar, er, well for guitar and for(?) picks, um, there, there are definitely picks that work better for me than, than others. Um, I, when I first started playing, I, I just had a big issue with, er, dropping picks while I'm playing or when I'm playing, the pick kinda moves to the side a little bit, so, I, I'm actually strumming with the, the pointy part. Um, so I really had to find the, the, kind of the, the perfect pick and, and then I, I tried those finger picks, you know, that, that attach to your toe, or, er, to your finger, um, or my toe. Um, and those didn't really work for me either. I, I didn't feel like, I, I just didn't, I wasn't comfortable with them. [No, sure]. Um, so, I mean eventually I, I was able to just find the right style of pick, um, cos I, cos I did try the really light picks too, like the really flimsy light picks. Um, and I could definitely play with those but they're, they're so light and they're so flimsy that it doesn't even, sometimes it doesn't even feel like I'm, it didn't even feel like I could get much volume, you know, er, volume as a, er, talking about, you know, the actual audio but also just, you know, just like the, I don't even know how to explain it, but the volume of, of the guitar, you know, and getting the most out of it, [sure, yeah], um, cos the, cos the pick is so light. [Yeah]. So, so, now I have, I've, I've found a perfect kind of pick; it's like a medium pick but it's also has that like, it has that, at the top of it where you hold it, it has these, er, what is it? I think I have one around here somewhere. [Pause]. It's kind of like Velcro a little bit. [Right, yeah. I've got you, yeah]. Yeah, so if it, it, it's like a little bit of Velcro where I hold it and it stays, um, but

now often, more, er, more often, I don't play with a pick at all and I even just strum, just with my toe, [Right, yeah], um, and, and then, then a little bit with my, with my nail too, just a little bit – er, just gets a different sound. So, so, yeah, I, I, through, through trial and error and just kind of figuring out what's best for me, um, I think I was, was able to, to just make it work.

RM: Sure. Okay, great, thank you. Um, [yeah] so, I'll move on a bit now to more of technique stuff. Um, so, you've stated before that you'd try and play or you'd do things as standard as possible, I suppose. Um, do you find that you automatically do this for everything? So, you, you'd do this to simplify matters or do you go through other methods to try and see if actually, oh, that might be more simplistic for me?

GD: Um, you know, I, I think first and foremost, I, I, I've always tried to see if I can, if I can, er, do it without changing many things about it. Um, so, I remember, I remember learning guitar, er, or wanting to learn the guitar and kind of doing some research and knowing that there are other people in the world that do play the guitar too, er, with their feet. And, um, well, I, I, the first guy I came across, er, was, was, really, really good; he is really, really good still and I'm, I'm connected to him too and he's, he's incredible. Um, but he, he plays in a lot of open tunings. [Melendez?] [Right, yeah]. And, and he explained that to me and I had the chance to meet him, er, like two years ago and, er, and we, we were talking and playing guitar together and, and he saw that I was playing in standard tuning. And he was just, he, he thought that was really amazing; he thought that was really cool cos, cos he told me that when he first learned to play, um, he just started in open tuning. So, that way he could just, you know, put his, his toe on a couple of the strings and just play the notes and play cos, it's, it's all open. [Yeah, yeah]. Um, so, that's just how he plays and how he's always played but then he saw me playing standard tuning and, and, and he really complimented that(?). And that was, that was kind of my decision from the start, er, was the, you know, I, I knew about open tuning; I knew that I could, and sometimes I do just cos it's fun and, and it sounds cool. Um, but, um, but learning from the start and just saying and just kind of treating it as if, you know, er, I wanna play this guitar and I wanna, wanna keep it so that I could pick up the guitar, give it to somebody with hands and they could play it too. [Right, yeah, sure]. Um, so, so, I really, er, forced myself to, to see how the chords are played, er, the G chord, a C chord, whatever, a D chord; whatever it is, um, and whatever key and just figuring out, how, how I could do that. And, and, you know, certain keys are easier for me that might be harder for other people like the key, the, the key of E is very; I love the key of E because, um, I can play the, the C Sharp Minor; I can play the, the B; I can play the A and, and I, with my big toe, it's, it's very easy for me to, to hit those three strings by themselves, so, like a barre chord is super easy for me. [That's good, yeah]. Um, yeah, I mean I've, I've played barre chords first and, and I was like: "Oh, maybe I should always play with barre chords". But then, then I, I, you know, wanted to challenge myself more and figure out if I could do, you know, full, you know, er, full, just full chords. [Sure]. Um, so, so, yeah, you know, I think, I think, er, well, treating each instrument, for the most part, you know, if, if I cannot change much about it and keep it kind of standard, um, that's what I'm gonna do and, and, er, but, you know, try it that way first and then if, then if I need to make some adjustments or make some changes, then, then, then I'll, of course, I'll do that if, if that, that's what's needed.

RM: Perfect. Um, I just, sorry, missed a question about the, er, instruments, um, did you, [Yeah]. You just, you were just talking about there, about the, um, giving it, um, as is. Um, did you ever have to modify the cello, guitar, bass, or even piano in any way at all or did you like different strings or different tensions; moving things around I suppose?

GD: Yeah, um, let me think cos I, I can't say that I, that I ever did, you know, other, other than using that, that stand; that cello stand and then, then the, the bow definitely, on the cello. Um, but other than that, I, there's no, nothing else really that, that I've ever really modified.

RM: Um, that's good, yeah. Okay, um, so, you've mentioned about, er, numbering your toes I suppose for the, er, different positions. Um, did you try and use the same sort of positions that, that someone would use for their hands and translate it directly for your toes or did you find that, um, I don't [know], there were certain positions that were better for you or again was it just all trial and error?

GD: Um, yeah, you know, a, a, a lot of that was, was trial and error. Um, so, I think when, when I'm, I'm playing guitar and, you know, I'm playing a C chord or a G chord, I'm, I'm playing the same chord that everyone else plays and it, it's the same spots and same frets on the guitar. Um, but, you know, my positioning is totally different, you know, in, instead of playing with it on my, on my lap and my, my, my wrist is kind of wrapped around the guitar and I'm playing with the fin, with, with those fingers that, that people play with, you know, I'm playing it looking down and my, my toes are on the guitar, so, it, it's, it is the same notes and the same frets but, but I'm, I'm sure I'm using, you know, in adjacent to fingers with my toes, I'm, I'm sure I'm using different toes. [Um, okay, yeah, sure]. Um, and I, I, I think I've, I've realised to that people playing guitar are usually using four of their fingers, I think, um, because their thumb's usually wrapped around. [Yes, yeah]. So, so, I, I, I'm actually using, I use all five, I use all five of my toes, usually. But now, now that I think about it, I don't really use my middle toe that much. So, it's, it's interesting, I just kind of realised that.

RM: [Laughs]. Yeah, sure, yeah. Okay, that's great. Um, [yeah] so, actually I was gonna ask about, um, have any of your everyday tasks translated to playing instruments or have helped in translating to playing instruments and, er, vice versa?

GD: Yeah, you know, one, I think one thing that, that definitely, er, translated, er, from playing instruments is things like typing. [Um, yeah]. Um, yeah, typing on a computer; typing on my phone - most of the time, I, just out of preference, I, I usually only type with my big toes anyways. Um, I know, I know there, there's people who, who only type with like one finger on each hand. [Yeah]. Um, but then there's people who, you know, can type with all, with all five fingers and, and it, and it's super-fast. And sometimes, I'll do that, you know, if, if, if I'm typing and my big toe's on one thing and then the next letter or the next, er, yeah, the next letter is, is where my pinky toe is, so, I can easily just use those two toes. Um, so, I, I think typing is, is really the, the big one that translated really well. And, and just kind of that being, er, being flexible with my toes. [Um, sure]. Um, that, that was because of learning to play the cello and, and because of doing those exercises. And, um, so yeah, typing would be a big one; I would say definitely writing too – just kinda being able to hold things really firmly and, and hold a different, because a hand might, might spread(?), like,

so, being able to spread my, my feet, my toes the way I can. It's, It's not a crazy amount but it's, it's, it's good, I mean it's pretty good where I can, I can pick, you know, up things that, you know, you might not think I'll be able to pick up, you know, kind of larger things like big cups or, or big books or things like that. Um, because, because I definitely stretched my toes a lot too, er, just being able to, er, hit those notes on a cello, we did a lot of stretches as well, um, and I, I think that definitely translated into everyday things too, just kinda picking things up and holding things and yeah.

RM: Yeah, great, thank you. Um, so, you talked about, um, showing someone else the fact you use standard tuning when they use open tuning, um, have you found anyone request that you give them some, say, technique advice for playing with their feet? It could be like an online message or whatever or, er, someone who's having a particular issue with an everyday task, um, you know, write an email or a message just asking how do you do that or maybe if they've seen something in a video or, or documentary, er, piece and just said how, how do you do that?

GD: Yeah, that's, you know, it's, it's been really, it's been really cool because I, I had, I've had the chance to meet some families and encounter some families just through, through email; or through, through just, even just social media. Um, but then also, just through, er, er, traveling to and being, we'd go to different states and, and, er, some families who, who knew that I was coming to a certain event or coming to a certain, their, their, their own town or their own city. And I've met a, a number of, er, er, younger kids who also don't have arms. Or who might not have much use of their hands or of their arms and they, they'll use, they'll use their feet a lot, er, but, but they're very little. So, their, their parents, er, kind of were just telling me how, how it was for, for me growing up, and, and asked me some practical things about, you know, er, things like getting changed or, or eating or driving my car, especially that, that, that's a big one, um, how to drive a car if, if they're child will ever be able to drive a car. And, you know, I, I, I, I try to always make it clear, um, that I, I'm always happy to share, kind of my thoughts and my preferences and this, you know, this is how I do this or this is how I do that; this is how I learned to do this. Um, but, er, their child or, or, or an adult even, er, it might be different for them, you know. Um, and I think that's, so, the, the way they learn or how they decide they're going to do a certain thing, um, might, might be a, be a little, little different, you know. Er, I have a brother who also has no arms as well. Um, he was adopted from, from India and, er, he lives in, in Washington D.C. and, you know, takes the, the metro and, and pack, packs his briefcase to go or his, you know, er, backpack to go to his work and has, has a desk. And he does things differently, er, that I do, I, we get done some of the same tasks; he just does it differently. Um, so, you know, but, buttoning his shirt – er, he'll, he'll button his shirt, after he kinds of puts it on, so it's already on him and he's buttoning it with one foot. I, I will button my shirt on the floor before I put it on, you know. [Um, sure]. Um, so yeah, I would, I, I love the opportunity to be able to talk to people who have kids who might not have arms too or, or adults or teenagers. I, I met a, I met a teenager who didn't have arms, um, er, er, about a year ago and he was, he was in high school and struggled a lot and he struggles a lot with, with, with himself and, and, er, just getting through life and getting through school and, and doing all that. And, and a lot of what ends up happening is, it's more, a lot of what I end up talking to these people about is more on the, um, I guess, perseverance kind of mentality, you know, persevering mentality and, and, and being strong mentality. Er, because I, I think for, for, for

a lot of them, the physical things and the physical challenges will, will also come naturally. Um, but yeah, but I'm always, I'm always happy to, to give my advice and, and kind of what I did, as kind of like a baseline sometimes too.

RM: Sure, okay. [Yeah]. Um, so, er, er, I suppose you've done it more, er, face-to-face with these interactions but have you actually been, er, taught anyone, er, the cello or bass guitar, or has it been requested like an online lesson with someone?

GD: Um, you know, it, it, it hasn't, I actually haven't really done, I haven't done any online lessons or anything. Um, I, I remember being a kid and, and my brother who I mentioned, um, just kind of just for fun, seeing if I could teach him, you know, to, to play the guitar too. Um, he, he didn't really pick it up and, you know, he didn't, wasn't a fan. Um, so, so no, I haven't, I haven't exactly taught, taught people, you know. There, there've been, there've been little moments at these concerts that I've, that I've done where, you know, some family, a, a family with a child who has no arms comes up to me, and I, and I offer and I, and I kind of talk to the, to the kid and I'm like: "hey, did you want, do you wanna, you know, get on my seat and, and, and play my guitar?" It's on, it's off a stage and everything, you know, and it's still plugged in and the lights are still on, and I'm like: "Do you, do you wanna try it?" and, and then, they'll, they'll try it and I'm like: "Yeah, this is, this is how I do it, this is, this is, if you ever want to play guitar, just remember, this is just kinda how I do it". Um, but no, I mean to, to your point and really to your question, I haven't, I haven't at all, you know, it's, which, er, might be kind of, I think is a little surprising. And it's something that I've, I've, of course, would be open to doing. [Yeah, sure, sure]. Um, yeah, but no, I, I, I haven't.

RM: No, okay. Um, so, regarding, I suppose, all the techniques you use for instrument playing and everyday, do you think you've reached a point now you're fully comfortable with these tasks or do feel you're always altering methods in some way?

GD: Um, I, I think, I think overall, I'm, I'm totally comfortable with, with kind of just navigating through life. Um, but there's always gonna be moments and, and maybe little things that can be frustrating in a moment. Um, or things that I might have a little more difficulty with like, you know, getting open that impossible pickle jar to open, you know. Um, little, little things like that or, you know, I have a little plastic bag that I'm trying to put something in to, you know, to put in the fridge to save but the, the, to open it, it's, it's like that tiny little, you know, er, that tiny little open, you know(?), er, thing. And, and sometimes that can be a little bit challenging too. Um, but, but I mean, I think, I think overall I'm, I've, I've become really comfortable; I'm, I'm definitely fully independent, I, I don't really, I don't need help day-to-day; er, from morning to tonight, I don't need help with anything. [No, no, okay, great]. Um, so, yeah.

RM: Yeah, okay. Um, so, just for the final part of this interview, I'm moving on to, er, advocacy work. Um, so, [yeah] perhaps you could, er, describe some of the work you've done with different, say, non, er, not-for-profit organisations and perhaps name a few, um, that maybe, er, some of the work you do or maybe how music's involved in certain ways?

GD: Yeah, um, you know, a, a lot of, a lot of the, the work I've done in, in organisations, I've, I've, you know, played for and, and shared my story for are, are a lot of the, er, disability

kind of empowerment or disability awareness, er, organisations. And, um, a lot of what that's around is, is, er, just showing, er, people with disabilities, er, that, that, you know, anything's possible, you know. Show, showing them that, you know, they, they might have a challenge that they're facing, they might have a, an obstacle, er, but there's a way around it and there's a, there's a way through it or there's a, there's a way over it and, and, you know, sometimes we just have to think outside the box; sometimes we need, we do need to ask for help and that's okay. Um, and we shouldn't ever feel ashamed if we, if we need to ask for help, we shouldn't ashamed or feel embarrassed. Um, and, and I think, I think being able to share and, and hopefully encourage, er, these different places and these, these people, er, either people who have disabilities or people who work with people who have disabilities. Um, kind of show them that, you know, what, what they do matters and that, um, there, there's so much, there's so much potential for each and every person on this earth; I, I, I believe so, and, um, I think, I think that's just, I think that's huge. So, you know, organisations like, an organisation called er, er, Joni and Friends or John, Johnny and Friends, um, is a really big organisation that, that just look, just, er, cares for people with, with disabilities. Um, a lot of, a lot of adoption agencies too and adoption, orphan organisations, um, you know, kind of showing them that special needs children, er, um, are, you know, are not a waste, you know, special needs kids, er, er, do need homes, and, and look what can happen when, when a, when any child, er, is accepted into a home and, and given a family and, er, er, truly big things and good things can happen and I, and I'm, and I, I, I think that I'm, er, a testament to that. Um, so I mean that's, that's really, that's really my goal and, and hope is to, is to just shed light on, you know, it, it's not a bad thing, you know, being, being different shouldn't be looked down upon or shouldn't be, um, you know, I guess, it, it shouldn't be looked down upon and it shouldn't be seen as this kind of sad thing, you know. That's, I, I, I don't want ever to be like, ah man, too bad, you know, he, he doesn't have arms, that's, that's too bad, you know, and, and I've, I've heard that so many times in my life. [Yeah]. Um, wow, oh, or I'm sorry, you know, people will say I'm sorry. [Yeah]. Um, and, and I, I don't want that for me, um, because I don't, I'm not sorry, you know, I don't feel bad, no, I don't feel sad about my disability; I, I feel sad about other things because I'm, because I'm human and I go through other challenges in life that are more difficult than my physical challenges. Um, but, you know, that, that's really what I, what I hope to, to do is to, is to encourage people to look beyond their disability and, and chase after their dreams, er, er, no matter what.

RM: Sure, yeah, okay, that's great. Um, so, you've talked about, um, obviously teachers helping you, er, with your music growing up. Were there any people or organisations that assisted you, I suppose, in a, a, or played a major role in, er, your personal progress and musical progress in any, you know, apart from those teachers you've mentioned?

GD: Yeah, you know, one, one organisation that, that really played a big part in my life, er, for, er, my, my personal, er, life, er, is a, an organisation called VR, which is the, the Department of Vocational Rehab. [Right, yeah]. Um, er, er, for, for here in Virginia and, er, and, er, they, they're all over, you know, they're, you know, probably in every state; in most states. Um, but for, for me, they, they would, er, their organisation, and they're the ones that helped me, er, learn how to drive, [right, yeah], and drive a car. And, um, I mean drive, driving a car, you know, I, I, I never, I don't want to ever sound braggy or, I guess, bigheaded but I mean, I mean, truthfully, driving a car was another one of those things where,

I, I believed I could, I just knew I could do it, you know. [Yeah, yeah]. I just knew I could do it without altering anything, er, drastically, er, even though that was definitely in the conversation at the very beginning was, you know, er, yeah, you, you, George, you can, you can drive a car, er, we'll just have to, you'll just have to probably put a, a wheel on the floor or things like that, and, and I, I didn't think that I had to do that. Um, so, VR, er, was, was really awesome because they, they, um, they believed me too, you know, they, they believed that I could do it without, without changing anything and they gave me the opportunity to prove that. So, so, I, I would go there, a couple of times a month, er, when I was a teenager and, and I would drive around the course and take these driving lessons with this teacher who was, who was really, really awesome and really encouraging and really believed me and believed in me. [Yeah]. And, um, and, and, oh, that's kind of a lot of what it was, um, one because it was a requirement by the State, er, for someone like me to, to, to do this program; do these lessons; pass their test, um, to be, to be able to get my licence, um, cos, cos it's different than just going to the DMV and going through Drivers' Ed, um, because I'm different. So, er, it was a different process but they, they were really patient and, and they never once made me feel like I needed a whole bunch of things, um, unless, unless, unless, unless it was too difficult. So, for example, when I, when I first started driving, er, at, at this place and so, first, I was driving around, I was, I was really excited, um, really confident too like, you know, and I kinda didn't really want to be there, um, cos I, cos I, I mean I was a teenager and I'm like, why am I even here? I, I know I can drive. Why can't I just do my hours and get my licence, you know? [Yeah, yeah]. Um, but I started driving around just, and you really just drove around the campus when you first start, so, just drive around the, the little rows that they have. And, you know, she would say: "okay, turn your signal on". So, so, I, I, I drive with my left foot down on the, the gas and the brake and then with my right foot, I, I'm, I'm, I'm reaching up and I'm holding the wheel and, and that's, I, I can do that and that's how I drive, but then she would say: "Um, okay, you're about to turn right. Go ahead and turn your signal on". So, then I, then I found myself with my right foot trying to like, trying to reach around the wheel to, to hit the signal and, and boom, like even that's not 100% safe. [Yeah]. And, and it, it was, it was easy enough to do on this little street but then she was, she was kind of explaining like: "okay, I can see your foot is off the wheel when you're doing that, [yeah, yeah], um, and that's not good. [Laughs]. Your, your leg might still be kind of like up against the wheel". So, you, I can kind of like keep it a little bit steady while I'm doing it or while I'm hitting the signal, but, um, you know, she was telling me like: "But, you know, when you're, when you're going 80 miles or 70 miles on the highway and you're trying to change lanes; you're trying to get off an exit, you know, you're, you, you turn your signal on, um, that's a different story than driving, you know, 10 miles an hour on this little street". So, so, they, er, that was the one thing that they decided, er, we're gonna have to, figure this, figure something out here. So, what they did was they put together this little metal bar, [right, yeah], um, this like little lever bar that attaches to the signal and, and kinda goes up to the wheel, where my foot's at and basically, there's the signal - if you're looking at a, a, a wheel as a clock, the signal is at 2 o'clock. [Right, yeah, yeah]. So, that's where the signal's attached to and goes to, so, when I'm, I have my foot on the wheel, I can, I can hit it with my toe or hit it with my, the top of my foot while still having my foot on the wheel. [Right, yeah, yeah]. And, um, that, that was kinda of the one thing that they, that we modified and, um, and it, it's, it's just worked out. So, I think they, they were, they've been the biggest contributor, contributor to, to, to just me personally.

RM: Yeah, okay, great, thank you. Um, so, I'll move on to my final question. Um, so, from, er, the PhD, I'm hoping that, er, well, I've had an idea about, er, an online database or a knowledge base for repertoire, technique advice, um, on how to play an instrument, um, potentially making some instrument, adapted instruments more low-cost and, er, mass-produced, um, would you advocate for something like this for aspiring musicians and organisations?

GD: Yeah, yeah, I, I, I absolutely would. I think, I think, I think that's a really cool idea, a really, really great idea. And I think that would help so many people and a lot, a lot of people I know, um, and I'm sure a lot of people would want to be able to play an instrument and, and be able to do that but they don't know where to start or, or, or where to go, you know, when it comes to adapting and adapting it to fit their, their needs because there, there are so many different needs, [yeah], and, and if everyone's needs are different and um, so, I think, I think that's a great idea, yeah, yeah, I'd, I'd love to, er, be a part of that and, and know how I can, can be a voice for that too.

RM: Oh, that's great, thank you, okay.

GD: Yeah, yeah, I think that's really cool.

RM: Okay, thank you. Um, yeah, so that, that covers everything, um.

GD: Oh cool, okay.

RM: Again, just, just a thank you again. Um, as I've said before, um, once I've written up the thesis, um, and included your parts in it, I'll, er, send you a copy by email and you can let me know what you want in there; what you don't want in there. Hopefully, you'll want everything in there, but if there's the odd thing you're unsure about, just let me know.

GD: Yeah, I'm, I'm sure I will, yeah.

RM: Yeah, um, yeah, and thanks for, er, filling out the Consent form as well – that's really useful, um.

GD: Good, good.

RM: Yeah, and again, I'm sure it'll, it won't be a problem that once, er, the PhD has been published, I'll be able to send you a copy or send some link to where you can find it.

GD: Yeah, yeah, either, either way. If you're able to send a copy or, or, or a link, um, I'd, I'd just love to be able to, to read it and even share it to cos, cos, I think that's a really, I mean, it's an amazing project and I'm excited for, for, you know, what you're doing.

RM: Thank you.

GD: It's really cool.

RM: Yeah, well yeah, with the PhD itself, it's only really a study. But, and it's a bit unusual that I'm using it as a platform for this, essentially this database. Um, so but, yeah, you just have to, to go through the process, I suppose, um.

GD: Definitely.

RM: But yeah. Um, that's it. Yeah, um, thanks again and, er, I'll be in contact here and there, um.

GD: Yeah, sounds, sounds good, yeah. Thank, thank you for, for reaching out and thank you for, for letting me be a part of your, your thesis and, and, er, it's definitely an honour and, and, yeah, we'll, we'll, we'll keep in touch and I look, look forward to, to hearing from you and hearing how it's going and, and, um. Yeah, I think, I think it's gonna make a big impact. I think what you're doing is gonna make an impact and, and, and go on to, just help so many people.

RM: Oh well, thank you. Um, yeah, so, thanks again, George. Um, enjoy the rest of your day and I'll contact you some point soon.

GD: Yes, sir. Absolutely. Yes, you too. Have a, have a, have a good one and, er, yeah, thank you, thank you again for your, for your time and thank you for, er, for letting me a part, a part of this.

RM: No worries. Alright, thank you. See ya.

GD: Sounds good. Yes, sir. Bye.

RM: Bye.

Interview terminates at 01:03:17

Appendix 12

Commences at 00:48

VT: Hello.

RM: Hello. Hi Valerie.

VT: Hi.

RM: Hi. Yeah, it's good to speak to you.

VT: Yes, you too.

RM: Yeah, yeah, okay. That's great. Um, are you all good to start? Good to go?

VT: Yeah.

RM: Okay, great.

VT: Yeah, sounds good.

RM: Alright. Um, were there any questions or comments you had before we start properly or are you all okay?

VT: Uh, I, I don't think so.

RM: Okay, great.

VT: Yeah.

RM: Um, so, just for the first question would you mind, um, stating your name and giving a brief description about who you are and what you do?

VT: Er, sure. So, my name is Valerie Thomforde. I live in Lower? Massachusetts in the United States and I am a public-school music teacher. I work at, er, elementary and middle school, or erm, primary school. I teach kindergarteners and, um, grades 4 through 8 for chorus and music. Um, I was born with an atypical cleft hand. So, my right hand has a thumb and a pinkie. And I am primarily a pianist. Although along the way, um, I've also played violin, trumpet, trombone, and recorder.

RM: Okay, that's great. Thank you. Um, so, with the instruments you've just listed there, um, could you perhaps give some description of the process you went through to find some of the alternative techniques you used to play, um, with your limb difference?

VT: Yeah, absolutely.

VT: Um, so, my first instrument was piano. I started when I was 9. And I watched my best friend take a piano lesson and then decided I wanted to play. And went home and, and asked if I could take piano lessons. Um, we didn't have a piano at the time, but my grandmother gave me hers and I started learning. And the first adaptive technique that I started to use, I, um, figured out myself. Uh, my dad had, uh, played this little circus tune on the piano. And, um, he was playing three notes in his right hand and one note in his left hand. And I realised that for me, the best way to play that would be to cross my hands. So, before I even had a first lesson, I was already, uh, crossing my hands where there were more notes in the written right hand and fewer notes in the left hand. Um, my first two teachers were very supportive of me playing piano but did not give me really too much advice about adaptive playing. Um, I studied with them through eighth grade and then I, I stopped piano lessons for a year. And started again with a different teacher who, er, gave me much more background in terms of music theory and chord analysis. [Right]. So, then when we were looking at a piece, I had to leave out a note. I could figure out what notes were the most important notes to play. Um, and when I was a junior in high school, the piano professor from the University of New Hampshire came to do a masterclass. Her name was Arlene Kies. Uh, K-I-E-S. [Okay]. And all of this I can, I can recap later. [Yeah, it's fine. Thank you]. If you miss something in the beginning? or whatever, [Yeah. Okay, great]. Um, so, she came to my high school to do a masterclass. And by that point, I was already thinking about majoring in music. Um, and applying to schools for music education. Um, and was working on this Mendelssohn piece as my audition. And played the first part and at the very, very beginning, she stood up. She was maybe 5 feet tall and I knew she was looking at my hand. And I really didn't want her to just focus on that. Um, I never really got into competitions but I had done some evaluations before. [Right]. And, and people made comments like: 'Oh, that's such, er, amazing compensation in your left hand' and 'oh, you're amazing'. But don't give me enough feedback on how to improve. And I was just really afraid that was going to happen with Arlene. And so, in the middle of playing, I blurted out: 'Please don't look at my hand!' So, she sits down and, er, I continue to, to stumble my way through the piece. And then she gave me this great lesson on how to use the damper pedal, as I was pretty clueless at the time. And then she asked how I played this scale. It was this descending E scale in the right hand. And so, I played it and then she sat down and played it herself with just her thumb and her index finger. And that was the first time anyone had really emulated what I do and tried to get into my body. To figure out what I was doing and how I could do it better. Er, so, pretty instantly, I fell in love with Arlene and decided I wanted to study with her. [Yeah]. Um, I did apply to one other school but basically, I wanted to study with Arlene, so I did. And er, she spent so much time, so much extra time with me. Helping me to figure out fingerings and where to take notes in the left hand and where to cross my hands and how to use, er, my knuckles better. And, you know, she spent so much time trying to figure out how my right hand worked and how I could make it as powerful and agile as possible. Um, and she helped me figure out how to tackle nearly everything. Um, with my teacher in high school, we, we kinda tended towards pieces where I didn't have to make a lot of changes. [Right]. And with Arlene, sure, there are pieces I will never play and that's fine. But, you know, we, we tackled some really difficult pieces where we did have to do, uh, a little bit of rearranging here and there, but where overall, I could still

perform it. [Yeah]. Um, so, she was really the most important person who could ever influence my, my playing in terms of how I play adaptively. Um, [Long pause] that's mostly my piano story. Arlene taught me, uh, you know, everything, [Yeah, sure] nearly everything that I use today, um, in terms of playing adaptively. Um, and I can go back to piano, but just to mention the other instruments. [Sure, yeah]. So, when I was, uh, in fifth grade, I was 10, we had the opportunity to join band. And the band teacher talked to my parents. Basically, they decided for me that I was going to play trombone [Right], er, because I wouldn't have to make any changes. My, my right hand can hold the side easily enough, Um, and, you know, then it's just play like every other kid. [Yeah]. Er, so I did and, you know, I loved being in band. Um, the trombone was not, wouldn't have been my firstchoice instrument. [No, sure]. Um, but it was an instrument I could play and that was great, so, I kept playing. When I was in seventh grade, I switched to play the trumpet. Er, I thought the trombone parts were really boring and too easy and the trumpet[er]s looked like they had more fun! [Yeah]. So, I got a trumpet. I play with my left, well I don't have one anymore but, I played with my left hand instead of my right hand. And I also got a trumpet that had a trigger on the first valve side, so that I could, um, operate that trigger with my left thumb and play with my left hand. [Yeah]. Er, and then the third valve trigger side, I, I can use with my right hand. Um, so then what, you know, beyond getting that instrument, there really wasn't anything to adapt after that and I just play lefty. [Right, yeah]. Um, when I was in eighth grade, I started violin. Er, and [long pause], my right hand can hold the bow. Er, so I never used any adaptations for that. [Right]. Um, years later when I saw, um, other people with limb differences play violin, I thought: 'I wonder if I should've put something like, wrapped the frog of the bow to make it, it easier to grip in some way.' Um, which I've done a, a small amount of experimentation with and, ah, I don't think it makes a huge difference for me personally. [No]. Um, so that was violin. And then, um, for recorder, I got into recorder playing as an adult. Um, I played in third grade and I used the Allos? (Standard?) model that, that's all chopped up in segments. And I don't think we set it up the right way. I don't think, um, er, we plugged the right number of holes or anything. But we really didn't play too much in music class. We didn't get beyond maybe three-note melodies, which I could do anyway. [Right, yeah]. Er, but then, as an adult, I, um, got my degree in music education. And then, started training in the Orff-Schulwerk approach, and recorder is a big part of that. And I knew for teacher training, that there was a whole recorder class. And I wanted to play, uh, a whole lot more than I could in third grade. [Yeah]. So, I, um, got just a regular soprano recorder and decided I would play with my left hand on top, um, but use my pinky normally - you don't use your left pinky, but I, I could cover a whole four(?) with my left pinky. And then I really wanted to use both of my right-hand fingers on top of the recorder, but then I couldn't hold the instrument. So, um, I tried using a neck strap and that wasn't quite enough support. And, I, I realised that what I really wanted was basically a third arm coming out my chest to hold the recorder. So, my dad and I experimented and basically, what we ended up doing, which I, I still use this today, um, we took a, just a plastic thumb rest. [Right, yeah]. Um, since it, it clips on and attached a wooden dowel to it. [Right]. So, that dowel is coming out of my chest and it clips onto the recorder and is a brace. So, my right hand can go on top and press down and I can still hold the instrument. Um, so, that's what I figured out before I went to my first level of Orff-Schulwerk training, um, which meant that, of the seven holes on the front of the recorder, I can cover six of them because I couldn't, on the soprano, I couldn't play low C, but I could navigate my way around

everything else. [Um, yeah]. Um, and after I did my level 1 training, I went to this recorder workshop. The Park Nouveau Recorder Workshop(?) in Brooklyn, near Boston and showed, er, the guys there what I was doing and my brace and I had said; 'You know, what, what could I do to get a customised instrument? How could I play the full range of the recorder?' Um, and the, the guy working there, Eric Hoss thought about it a bit and, you know, looked at what I was doing. And figured out that, um, if I had a key on holes 4 and 5, I could use my left pinky to do both of those. So, I could play one or the other or both at the same time. Um, and that would allow me to play the whole range of the instrument. [Right]. So, they couldn't do the key work there and so I started asking around. Er, early music shops and, um, instrument makers and instrument repair people with outside, you know [expertise?]: 'Is there a way I could get two keys put onto a recorder?' And, um, they all said: 'That was really expensive and really difficult'. And I said: 'I know. This is what I want to do. Um, and I'm looking for grant money and all this'. Um, and I contacted recorder companies and all sorts of places and everyone told me: 'No'. Um, and then eventually, someone told me about, um, Peter Worrell in the UK, eh, do you know of him? [Yes I do. Yeah, I know of him, yeah]. Yes. So, eventually someone gave me Peter's name and, er, I reached out to him and he said he could do it. And, um, judging by what I had seen on his website at the time of other instruments he had made and adaptations, I thought he, he was just the perfect person to do it, um, and he did! And my, er, soprano recorder is beautiful and I loved it and then I, I could play, which was amazing. Um, so a year or so later, I commissioned him again to put keys on an alto [recorder]. [Right]. Um, and then, several years after that, um, I commissioned him again to put keys on a Renaissance F recorder. [Right]. And that has been really great. I, er, I studied, I took recorder lessons for a while and I played in some recorder consorts. And, um, way back in fifth grade, I had told a friend apparently that: 'I would have wanted to play the flute, er, if I had 10 fingers'. And I didn't. I played the trombone, which I didn't really like the sound of the trombone but it was very practical. [Yeah]. And so, being able to play the recorder fulfilled that, that desire and had for a flute-like instrument. Um, and yeah, I, I'm so lucky to have those instruments - they're beautiful. {Yeah]. And it gave me a whole new way to make music.

RM: Yeah, that's great. Well, thank you. [Um, yeah]. Er, yeah. I was actually gonna mention that, um, when you said, I think it was along the lines of: 'If I had 10 fingers, I would've picked the flute'. Um [Yeah], were you discouraged in any way by, um, a teacher or something from learning the, the flute or did you just make that decision yourself thinking like you said the trombone was more practical?

VT: It was, you know, it was something my parents and the band teacher kind of decided for me. [Right, yeah]. Um, and I didn't really question it. They kind of said: 'This, this is gonna be, this will work for you'. Um, and yeah, I mean I, I wanted to be in, in band so much, I, I didn't, I didn't question it at the time [Yeah], um, too much, [No]. Um, and by then, I was also playing piano, which was definitely my choice. And um, yeah, so, so, at the time I, I just said: 'Okay, I'm gonna play the trombone and I can do it and that's fine'. Um, and I think because I was a very motivated music student, I was able to still have the motivation to practice trombone. Though I do think that, um, you know, people and kids especially do gravitate towards instruments of different timbres. And, in general, er, are much more motivated to play an instrument they like the sound of [Yeah], than one that

they don't. [Yeah]. Um, so, you know, as hard as it is to get customised instruments, especially for woodwind, um, you know, it's worth doing for people who really, really want that sound [Yeah], want to be able to do that.

RM: Um, that's great, yeah. Um, so, with, um, these techniques and devices, could you possible give maybe an amount of time where, how, how long the device took to make until you were fully comfortable playing the instrument or how long a certain technique took before you were fully comfortable using it on the instrument, [hmm], if, if at all possible?

VT: Yeah, um, hmm, [long pause], that's a tricky question, um.

RM: Yeah, you can be, er, general if you like just maybe, I don't know, maybe even like 3-5 years or something, as an example. I, I don't need specifics. It's just trying to sort of highlight how long these things take, I suppose.

VT: Yeah, I mean, the hardest part for recorder was getting the actual instrument in my hand. [Um, yeah]. And that process to acquire the instrument, um, now, you know, learning music and learning any instrument is a, a lifelong journey. And, um, you know, saying [laughs], say we went back to when I was 20 and didn't have children and didn't have a job and could practice many hours a day. If I was playing recorder at that time and spending many hours a day, I would really finesse the technique [yeah], with my left pinky to go from key to key. [Yeah, yeah]. Um, in a way that I know just because of where I am in life, like that's not gonna happen and that's okay and I'm not aiming to be a professional recorder player and, and it's alright. [Yeah]. Um, but you know so, I feel like to, to really, REALLY, REALLY master that technique of handling those keys, um, [laughs] would take many more years than I, er, and many more hours than I will, I will really ever put in. [Sure]. That being said, you know, I, I have practiced and I've gotten better and all of that, with the time I have put in. Um, and in terms of piano techniques, um, [long pause], hmm, I feel like with each one, [long pause], uh, I've started it because there's a certain situation that requires it like crossing my hands. [Yeah]. Um, but then really, it's something that I continue to work on, wherever it comes up. [Um, yeah]. Um, oh, that's what I forgot, um, when I was a Senior in Undergrad, er, Arlene, my piano teacher, said to me; oh, and that was another part [laughs], I'll come back to everything [Laughs]. Er, er, which do I want to do first? I'll go chronologically. So, I've had 3 surgeries on my hand. Um, when I was born, there was a lot of webbing in between my fingers. [Right, yep]. And I couldn't open them very wide. And right after I was born, my parents were told about, uh, this great surgeon, Dr Joseph Upton, who specialised in working with people with limb differences. And when I was 10 months' old, he did something call a Zplasty(?) [yeah, yeah], where he cut the webbing in the shape of a Z and stitched it back together, so I could open wider. And then, when I was 3 and a half, he did the same thing; another Z-plasty(?) surgery. And he also rotated my pinky so it was slightly, er, apposable with my thumbs, so it was easier to pick up objects. [Yeah]. And um, life went on and I went back for my yearly check-up, every year. And when I was 15, I could reach a fifth on the piano and I could very, very nearly reach a sixth. [Right]. And Dr Upton said to me: 'Is there anything that you would like to do with your hands that you can't'. And I said: 'Well, it would be great to reach one more note on the piano.' And he looked at the webbing

that was left and said, he could do that. So, when I was 15, I specifically had another surgery to reach one more note on the piano. Um, so, I can reach a sixth and I play sixths all the time. [Yeah]. And now to skip ahead to my Senior year of Undergraduate, uh, Arlene said to me once: 'You know what? It would be really convenient if you could, if you had something that could play an octave. Because, you know, sevenths don't come up that frequently, but octaves are much more frequent, and like that would be nice, if you could play it'. Um, so, I took two pencils and crossed 'em and put a rubber band in between, uh, which was easy to hold. And uh, used that to kind of stamp out octaves with my right hand. [Yeah]. Um, eventually, I had a wood turner create a device for me, uh, with, I put cork on the end, so it was, er, less crockety(?), and um, I can play octaves. So, the only time I can really use it is if there is an extended passage of just octaves, and where there is time to pick it up and put it down. [Right, sure]. Um, but there, there are plenty of places that do that. Um, I just played, er, er, Pizze tu a tango(?) for two pianos. And at the end, um, this is actually a place where I cross my hands as well, the written left hand is just octaves for 3 and a half pages, and the right hand has four-note chords. So, I cross my hands and use the octave device in my right hand, and then I can play every single note that's written. Um, so, I've used it in, in several pieces, mostly chamber music. Um, and, [long pause], um, yeah, that, that's the octave device.

RM: Oh, okay. That's great, yeah. Um, so with the, er, techniques and devices you've used, have you, [yeah] er, passed them onto other, er, students or other people who've been interested in what you, er, you're doing?

VT: Yeah, um, so, I, um, for a very, very brief time when I was in Undergrad, I did teach a piano student who had Amnionic Band Syndrome. [Right]. Um, he had, I, I think he had ten fingers but most were shorter and didn't, some didn't have, um, as many knuckles or any knuckles. Um, and so I was very excited to teach him and to, um, help him with things like; I slide my fingers a lot [yeah], so, um, I'll play two notes in a row with my pinky from, especially from a black key to a white key depending on what comes next. Um, and I was very excited about sharing all these techniques, um; the little kid just wanted to play baseball; he was not really interested in piano [laughs], [yeah], so, he didn't end up studying very long. Um, I am part of a support group called the Helping Hands Foundation, er, which is kind of equivalent to Reach in the UK, [yeah, okay], from what I gather. Um, and every year, well the past two have been virtual but, every year in the Winter, um, we get together for a weekend and a lot of kids bringing musical instruments to share. And I have been able to, um, you know, briefly coach kids, er, at those events. Um [long pause], yeah, I, I don't know of anyone else who has an octave device like I do for piano. Um, I have given away several braces for recorder, [right, yeah], um, that I've made. And, um, yeah, it's definitely something I would, I would love to do more of, um, [right], eventually. I'm, um, the mother of a 2-and-a-half-year-old and I'm pregnant with my second kid due in March. [Oh, right. Laughs]. So, er, being [laughs] a working mother has kind of pushed all of my, my adaptive music, um, aspirations [sure], to the side for a little while. [It's alright]. Um, actually I was very excited when you, when you reached out to me so I can, kind of, you know, say I'm involved in [laughs], this work, um, because right now, I'm on my own, not doing a lot.

RM: No [laughs], fair enough, yeah. Um, so, I've seen you discuss, er, elsewhere about, as you said, the holding devices that they should be effortless. But with your experiences, have you found that most of them aren't effortless?

VT: Um, hmm, uh, so, the recorder brace with the neck strap that I use for recorder, works pretty well for me. Um, I didn't really try any others. [Right, yeah]. I don't know what others are out there. [Hmm, that's fine]. Um, [long pause] yeah.

RM: No, that's fine. No, that's no worries. Um, so with the, er, adaptive recorders, you spoke of, um, getting funding. Could you maybe describe the process and was that easy, difficult?

VT: Yeah, so, when I, um, got my soprano recorder, it was funded by an organisation called the Play Foundation, which no longer exists. [Right]. But it was started by a woman whose feet and hands were amputated as a result of Sepsis, uh, a Sepsis infection. And um, she started this non-profit to fund projects for, especially for kids, um, in Sports and Arts. And um, because I, er, was a music teacher working with children, they, er, accepted my grant application. Um, I did look at a lot of different organisations and tried to find funding; that one was the one that worked out. Um, then for my alto, I, I didn't, the, I, I paid for the majority of the instrument but I did get some funding from the American Recorder Society. [Right]. Um, I had joined the American Recorder Society and saw that they had grant opportunities. Um, so I, I put in an application for that. Um, and I've since written a bit for them as well. Um, and those were the only two times I've ever applied for, and gotten, um, funding. [Yeah, yeah]. Um, and I, you know, feel very lucky that, that I did. [Hmm, yeah]. Um, it definitely took some searching to find something that would be suitable. Um, and as I said the Play Foundation no longer exists. [Sure]. So that's not even an opportunity anymore.

RM: No, sure, okay. Um, I'll move on now to, er, your own teaching. Um, so, um, maybe if you could describe some of your experiences as a teacher to musicians with limb differences. So maybe, um, issues like, like you said with technique; not your own technique and devices but maybe used for other people and maybe, um, because I remember you said with the recorder stuff, that you tried to use a standard model as possible, so, i. e. could something like that translate to somebody else or would you always have to find individual, er, device and techniques for each student, um?

VT: Yeah, um, so, so first of all, I wish that, um, I could do more, specifically teaching of musicians with limb differences. Um, I, I, mostly I teach in a public school; I just teach [sure, yeah, yeah], whoever happens to be there. And actually, I've never, I've never had a student with a limb difference. [Oh, really. Laughs]. In the public school [yeah], [oh right], um, you know, I, I will hope for, for encountering one always. Um, I do have a lot, through, through music teacher connections, often times other teachers will reach out to me [yeah, yeah], asking for ideas and solutions for their students. So, I, I actually feel like I've done more work in that role, advising other teachers than I have directly teaching kids with limb differences. Um, yeah, I, and I do emphasise this, especially when I'm talking to other teachers, that everybody is different. [Yeah]. And the goal is really to figure out how to use your body most effectively. Um, when I was in college, Arlene really wasn't keen on

me learning, uh, left hand piano repertoire. [Right]. Because she wanted my right hand to be as strong and as good as possible. [Um, yeah]. Um, and, you know, I dabbled in the Ravel Concerto for the Left Hand and, and Skriamen(?) and stuff, but, but really I played two-handed repertoire. [Yeah]. Um, and that was what Arlene wanted me to do. In a similar way, um, I, I knew there were one-handed recorders already out there on the market. And I specifically, did not want to get one [no], because I have two fingers on my right hand [yeah], and, and I can use them. [Yeah. That's fair enough, yeah]. Um, yeah, so, uh, I do think finding individualised solutions is really the best way to go, even though that is trickier [yeah], especially when it comes to customised instruments. Um, but in the end, I think that will allow the musicians to get further.

RM: Sure, yeah. [Yeah]. Yes, so, yeah because I remember, um, reading one of your blogs about, er, I think it actually might have been the article, about the small number of adapted instruments in the classroom. Um, do you think this could be improved in some ways, i. e. using, er, like digital instruments or, um, could school funding be geared more towards specialised equipment or something like that?

VT: Yeah, um, [long pause], yeah, I think having many options is obviously ideal. Um, I know in the United States, uh, if a student is on, uh, an IEP – an Individualised Education Plan – um, sometimes they can get funding. So, um, a friend of mine got one of Peter's one-handed recorders, um, which are not cheap [no, no], I mean they're beautiful, um, when he was in, in elementary school because he had an IEP and the school, uh, funded it. [Yeah]. Um, he's actually since passed that recorder onto me, and through the Helping Hands Foundation, I loan it out to other kids. [Yeah]. Um, uh, he's the only one that I know the school has really paid for a lot of adaptive equipment. I, I mean, I'm sure there are other instances of it. [Yeah, yeah]. Um, [long pause], yeah, I think there are probably some instruments and adaptations that would be more easy to just have in the classroom. I'm thinking of, um, mallets with thicker handles that are easier to hold. Um, I have one of my ukuleles at school, trump[et], er, with the strings flipped so it's a lefty instrument. [Um, yeah]. Um, and I think, you know, those kind[s] of adaptations are, are much easier than having a one-handed player there(?), [yeah], whoever needs it, you know. [Yeah, yeah, sure]. It's just, it, it doesn't come up frequently enough that it, that it makes sense. [Yeah, sure]. Um, yeah, er, I do, I, so you must know of the OHMI Trust? [Yes, yeah, very much so]. Yeah, um, I, I saw recently that they have this whole loan system with all these instruments out for loan, which is brilliant. [Yeah]. I wish we had something like that in the United States, like I've got my, this one-handed recorder that Eric gave to me that I loan out to other kids now. But, um, you know, maybe that's something that I try to establish here because that's really a huge barrier; just getting the instruments, um, into kids' hands. Um, [long pause], [um, that's fine], yeah, I don't know.

RM: Yeah, actually, um, going off your point about, er, or, er, with all the OHMI work. It really seems that they've become sort of like an international hub for um, [yeah], most of the stuff we're discussing, um, maybe because we, you've said like the US could do more. Do you, do you know why this is the case or how [laughs], the situation could be improved?

VT: Well, I, I don't know why it's the case. [No]. I, so, I went to the OHMI conference in 2018, um, and was amazed. There are so many organisations with Drake Music and [yeah], um, there, there just, you know, [seem] to be so many groups there. And, um, is it, where you're at, um, University of Leeds that has that whole disabilities studies [yeah], program? [Yeah, yeah, I think so. [Yeah]. A whole department for it, yeah]. Yeah. [Yeah, yeah]. Yeah. Um, I just don't know of, of groups like that here. I'm, yeah, in, in the same visible way, um. [Sure]. [Long pause]. [No, that's fine. Don't worry about it. It's fine. It's fine]. Yeah, [laughs], uh, I feel like it would be a good thing for the United States to have, for sure. [Yeah, well, I've], um, [yeah, just in my research I've just found that there's a disparity between UK provisions and US provisions, I suppose]. Oh, definitely. [Yeah, yeah]. Yeah. [Um, that's fine, yeah. I'll move on to, uh, oh, sorry]. I mean there are, there are plenty of issues with the United States besides that. [Laughs]. So, [yeah, fair enough, yeah], um, yeah. [Yeah, we'll leave it there]. [Laughs].

RM: Er, there was another, um, interesting point, I think it was when you were talking about your adaptive recorder saying 'getting customised instruments was simply finding someone willing to embrace your idea', um, have you found, [yeah], since then that the situation has improved or do you think it's still, um, the same as it was back then?

VT: Hmm, um, [long pause]. So, back then hasn't been that long. I think I got my soprano recorder in 2014. [Right, yeah]. I imagine it's, it's pretty similar but I think, I also think, um, the more people that do this, the more people who hear about it, um, the more people who will think it's possible. [Yeah]. Um, yeah, so, you know, now if I, if I went to some of those instrument makers that I reached out to years ago and who decided it was just too difficult and showed them: 'Hey look, this is my instrument. This is what I can play. This is, is what it allows me to do', [yeah], um, I have to imagine that, that people would be, yeah, supportive and impressed and think: 'Oh well, okay, it is possible'. [Yeah, yeah]. Um, and I, I think oftentimes, if you haven't seen something done before, you may jump to the, um, mindset that it's too hard or, or whatever. I mean, um, I think, I think one of the best, um, you know, it's a, it's a blessing for me in a way that my parents aren't musicians because when I asked them to play piano, they said: 'sure'. [Yeah, yeah]. And they didn't think, I had no idea it would be hard, they had no idea it would be hard. And, [yeah], you know, they weren't gonna stop me because they, they supported me trying whatever I wanted; gymnastics or baseball or, you know, whatever it happened to be. They wanted me to try and to figure out what I could do and, um, piano was no different. [Sure]. Um, yeah, um, I think, you know, sometimes, uh, in my public-school teaching, I, uh, think, you know, when my kids graduate, maybe they don't know anything at, may, maybe they haven't learned anything at all. But at least some day, um, if they see another person with a limb difference, they'll think to themselves: 'Oh yeah. My music teacher had two fingers and she could still play piano and guitar and everything else and she was, you know, [sure], um.' And that just change in perception I think makes a difference.

RM: Sure, yeah. That's great. [Yeah]. Um, I'll move on, er, I saw your, did a recorder survey of, er, teachers and saying how some teachers seem unprepared or unaware of how to teach, er, students with limb differences, [yeah], um, obviously that was specific to the recorder, but do you think that translates across the board to many different instruments and many different, er, you know, places of education, I suppose?

VT: Absolutely. [Yeah, yeah]. Yeah. [Um]. Um, there, there is a, a, well, I can't speak nationally about this. Um, but music teachers in my state of Massachusetts, now are required to take courses on special education, [right], every, every couple of years now. Um, which is a very, very broad category, of course and includes disabilities, so, of all kinds. Um, but, you know, I, I think, er, training is needed to learn. [Yeah, yeah]. Especially if it's with a, in a circumstance where you don't have a sit-in like that, and then some day you do, and then you think: 'what do I do now?' [Yeah, sure]. Um, yeah, um, I certainly never had any training on how to adapt music for people with physical disabilities before. [Hmm, yeah]. Um, you know, mostly what I know is through personal experience and, [sure], and because I'm interested in, in this field, so, [yeah, yeah], um, it was never anything that was part of any curriculum, [sure]; there are classes that I've taken.

RM: Um, yeah, um, so, what sort of improvements do you think could be made to help teachers?

VT: Um, yeah, definitely more training. Um, er, [long pause], someday I, when I, um, have, have talked to, oh gosh I forgot his name, Alex someone [Lubet?]. There's a Professor in the United States, I think in Minnesota; this was years ago now, [okay], er, who interviewed me and, um, teaches, actually teaches a class on Music and Disability, which unfortunately, I don't think there are many in the United States, [no], but he happened to be teaching this class. Um, and, you know, we were talking one day about having, you know, a, a much more comprehensive online, er, basically a database, kind of like, er, Wikipedia for music adaptations. [Yeah, yeah]. Um, where it was in one, one centralised place and people could add to it and where, um, music teachers could just access that resource and see other examples, er, especially for those situations where: 'oh, I, I've never taught a kid with a limb difference before. I've never taught a kid who, um, you know, has this mobility challenge or whatever.' Um, yeah, so, I think more, more courses, uh, in music education training, in general would be great, and then also, um, just a more comprehensive online, um, presence. I, I, you know, I'd worked on that blog before I was pregnant with my first son, um, and, you know, that was something I did on my own. [Yeah]. But, it's not very comprehensive at all, [no, sure]; it's a couple of articles here and there, and you know, you, you, what OHMI has is great, and what, uh, some other resources out there is great too. Um, but I think that's kind of, kind of hard for the average music teacher to just stumble upon. [Yeah, sure]. Um, [long pause], yeah. [Yeah, no, that's fine, yeah, um]. Anyway, OHMI really seems to be the leading organisation, [yeah, yeah], from what I can tell, [yeah, needs saying?], and, you know, if that can grow and expand and, um, yeah, I think that would be really, really powerful for people across the world.

RM: Yeah, oh, that's great, thank you. Um, moving on to, now to, er, 3D-printing, um, stuff. So, maybe, [be]cause I remember seeing you use the, er, [yeah], open-source Tinkercad, um, to 3D-print your own, er, [yeah], devices. What, how are your experiences of 3D-print, 3D-printing been?

VT: Um, so, I've only done the recorder brace. Um, and, um, basically, I think it's just a, a great technology because it's so easily customisable. Um, er, I had a, the, usually an engineer and teacher at my school, um, and my school got a 3D-printer, so that was where

I first experimented with it. Um, and I think there're, I think there are really great possibilities, um, because it's so easily adaptable. [Yeah]. Um, I think there are some limitations based on right now on just the materials, especially just, er, not in a, um, more professional..., I don't know the right terminology. [Yeah, sure]. But with the, you know, the, the certain plastic that we had in our engineering room at my public school, um, you know, you couldn't make an instrument out of that, [no], and have it sound any good. But you could make a holding device; you could make a brace; you could make a mount. Um, and that's what I think could be really great. I know, um, a, a lot of students with limb differences struggle to hold instruments and, um, if there aren't devices on the market but you can make one with a 3D-printer, that's a, a really relatively inexpensive, er, way to make a piece that's exactly the shape you want. [Yeah]. Er, so, I think there's great potential; I just haven't done much more experimentation besides that, [no, sure], er, brace.

RM: Yeah, that's great. Um, move on, er, because you talked about, um, having surgeries but there's also, I've come across sort of occupational therapists and physical therapists. Have you ever, um, had the services of an OT or a PT, um, when playing music?

VT: I, no I never did, [no], um, or not even for not music, just in general, I never did. [Right, yeah]. Um, yeah, and, er, the Helping Hands gatherings, I do hear about a lot of families that, especially with little babies with limb differences, DO have OT services and PT. Um, and I never did, I think, [no], it was less common back in the, the late 80s, early 90s. [Sure, yeah]. Um, And I don't know, you know, my parents saw me crawling, and picking up Cheerios, and, 'oh yeah, she's fine. What does she need anything for?' [Yeah]. That was really pretty much their, their, um, I don't know, attitude, [yeah, sure], towards many things, like 'oh, she's fine. She can do it all'. [Yeah, yeah, fair enough]. Um, I'm not sure that, er, it would've made a huge difference as a kid. [Hmm, sure]. I think for me personally, I think for other kids, it, it's hugely beneficial. [Yeah]. Um, yeah, especially with, um, foot users, [yeah], um, I know a friend of mine who is missing both her arms, you know, as in(?), OT and PT for years. And that's where she learned to use her toes as, as individually as she does. Um, uh, yeah, so I never had any of that. My piano teacher in college did spend a lot of time just figuring out how my hand works and how my knuckles work and how, how to best use it on the piano. [Um, yeah]. Um, but she was trained in, in any kind of therapy. [No, sure]. Um, she was just a really caring piano teacher. So, yeah, um, [long pause].

RM: That's fair enough. Um, yeah, so, you described, um, Helping Hands, um, being an organisation, you worked with. Are there any other organisations you've worked with, um, at all, in [for?] that kind of amount of time, I suppose?

VT: Uh, no, [no], Helping Hands has been the only one. I've been a part of it my entire life. Um, it was founded just a few years before I was born in Massachusetts, by a bunch of parents of kids with limb differences, [yeah], um, who wanted to form a support group. Um, and that's the only one I've been a part of, but it was really, it was huge for me as a kid, [Yeah]. And for my parents, you know, my parents were very nervous and didn't know what I'll be able to do, um, and then they saw all these other kids, being kids, and they, they were able to relax a little bit. And I think, um, what that meant for me was they

were able to parent in a way that encouraged me. I, I never, um, felt ashamed of my hand. Um, I, I never felt like I couldn't try something because of my hand. And, and I credit that largely to my parents and my parents being a part of Helping Hands. Um, and for me as a kid, I saw, um, I saw this kid Mike who was missing a hand to play the trumpet. And, er, you know, I saw kids doing everything, so, I never hesitated myself. Um, and then, as a, a teenager and then an, an adult, uh, I, er, remained with this organisation because now it's my turn to give back to newer families and to, to pay it forward and to continue, um, continue all of that. Um, occasionally, I've, I've listened to TED Talks where, even we've had guest speakers come to Helping Hands who didn't grow up with that community. [Yeah]. And, and sometimes, you can see, a, a real difference there, um, where people have really had to, had to struggle with that part of their identity. Um, not that, not that everyone at Helping Hands doesn't have to, you know, figure out who they are and, what, what their limb difference is. Um, but I always got to see kids with limb differences twice a year, [yeah], and that was really, really huge for me.

RM: Hmm, that's good, yeah. Um, so, I'll move on now, er, to 'Another Way to Play'. Um, when you started that was that just, um, a case of, as you said, having an interest and just wanting to highlight to people what's out there, I suppose?

VT: Yeah. [Yeah, yeah]. Yeah, um, so I'd, I'd started a, another instrument adaptations website before that and both of them came out of just a, a personal interest and also, um, having music teachers ask me questions. [Yeah]. And I figured: 'well, if I hear so many questions from just some music teachers that I know, there must be other music teachers out there, [yeah], who have similar questions and also, there must be other, uh, people with limb differences out there with similar questions.' Um, and, you know, [laughs], when I was born, we didn't have the Internet. So, there were, [yeah], there were certainly no, er, Internet opportunities for learning about instrument adaptations but. [Yeah, sure]. Um, er, yeah, I think, er, it, I thought it would be useful and I thought it would be something that I would have fun writing about, so, [no, that's good], that was it. [Yeah, fair enough]. Yeah. [Yeah].

RM: Um, so, yeah, that moves me on to my final question really, um, because you were talking before about, um, a database for education. Well, part of my, um, potential outputs would be to pitch the idea for a database or a knowledge base for, um, like repertoire, technique advice, prosthetics, um, [yeah], all to help not just musicians; [also] organisations, instrument makers, but also, I'm talking about the occupational therapists, physical therapists, and there's also, I'm learning more about prosthetic makers and sort of the role of hospitals themselves in this process. Um, [yeah], so if I were to, [that would be amazing], yeah, um, what, what do you feel are some of the, um, things I'd need to look out for and maybe some of the issues, issues maybe you've encountered when you looked at it yourself, or maybe that I need to consider?

VT: Hmm, um, [long pause], I mean it sounds like a great idea. [Laughs]. Um, and like the greatness of the idea would, er, would, er, be far greater than any of the issues with it, [laughs], I think. Um, I know when I was talking to that Professor, he was talking about just the, you know, the financial costs to maintain such a database. Um, er, you know, but with, with the right funding from finding the right people, [yeah], that, that can be

overcome. [Hmm, yeah]. Um, [long pause], yeah, I, that sounds like such a fabulous idea. [Ah, thank you, yeah], er...

RM: So, yeah, um, if this were to come about, would you, which I(?), it sounds like you would be, but would you advocate for a project like this?

VT: Oh, absolutely, [yeah], yes.

RM: Thank you, yeah. Um, so, that's all my questions really. Um, is there any questions or comments you have before we finish?

VT: Um, yeah. What led you to this work?

RM: Um, at, er, university, I was doing a Music Composition, er, course, and in the final year, we, we could do a dissertation. Um, and I was looking into just disabled musicians in general and how, er, they were playing instruments. And just how, different, and, and how sort of, um, different their ideas were and how it was not just adapting the instrument itself, its complete redesigns of instruments or its, you know, er, adaptive techniques and that whole world really fascinated me. Um, so, through the years, it just went from that dissertation was on disabled music, musicians in general. And then, over time, it's become, led to, er, limb difference or as, like the absent limbs and digits that I'm doing but essentially, er, limb differences. Um, because I felt that's the one area where you've got what I'm talking about with the database. It's got prosthetics, er, you know, you've got your, er, occupational therapists, um, along with teaching and, um, the instrument makers, device makers. [Hmm, hmm]. And just seeing that bringing all that together would be, obviously, great, but how difficult it is and what I need to consider, and it's all just (went?) further and further down. And then, you know, it took a lot of time to get from my Masters onto the PhD itself because I've been; initially, I was going to look into the designing of instruments or alternative instruments, [hmm, hmm], um, and just realising how much of an undertaking that was. And I'm not, [yeah], an engineer, um, [yeah], of any kind, so, then, I'd need some sort of training, which again is more money. So, I needed to, I think, go more down the theoretical side and I mean having conversations like this is brilliant because it just gives me a great idea of what's needed and I'd much, [yeah], rather be an intermediary between all these different fields, I suppose.

VT: Right, um, did you in your research come across Inga Petry and her mother, Jennifer Petry. [Yes, yes I've], Inga, oh, you have okay. [Yeah, no, carry, carry on, it's alright]. [Laughs]. Uh, oh, great. Yeah, uh, do you know about the Cincinnati Adaptive Music Project, [yes], which, [yeah], okay, great. Yeah, because that was really, I, er, I worked at that for one year and, and that was brilliant. To specifically to bring together engineers and music teachers, um, you know, and that, that's the, that's the issue – music teachers are not engineers, [yeah], and engineers don't know enough about music. [Sure, yeah]. Er, so, you really need both to come up with solutions, I, I would I thought that was a really, [hmm], great idea that Jennifer had.

RM: Yeah. So, what, what was your, um, experience at the camp? What, did you have to teach someone specifically?

VT: I did. I, I, so, I taught piano. [Yeah]. Um, er, I taught Jennifer's second daughter, um, Elena. [Hmm]. And, you know, I, I had this really, really, er, er, what's the, what's the adjective I want? Um, had this moment anyway where Elena was playing piano with her toes and at the end, [yeah], of her little piece, she played a chord and, with one foot, and I had this moment where I thought: 'wow, that was amazing'. And then I had this second moment of: 'and now I need to teach her to make it better, [yeah], because she doesn't want to just hear, 'wow, that was amazing". [Hmm]. Right? [Yeah, yeah, got it(?)]. Um, and, you know, I like, it, it gave me some insight on how other piano teachers see me and I get, and I get it. I really, [yeah], I do understand why they think it's amazing and I want to get better. [Yeah, sure]. Um, yeah, [oh, that's great, yeah], so, that, that was a very memorable moment from that camp. Um, and, uh, you know, I got to, I got to watch Jennifer work with the engineers and, and figure out the best bow, uh, prosthetic for some kids for string instruments. And, um, yeah, it had, you know, there was the right knowledge base there, [yeah, yeah], to come up with something that worked. Um, I've seen a lot of, of prosthetics for string instruments that are very heavy and clunky. [Yeah]. And, um, and that's hard because, you know, the, the kid is trying to learn a string instrument, which is hard enough in itself, [yeah], and if you have equipment that doesn't work, um, [yeah], it's hard, [sure, yeah], and discouraging, [yeah], yeah.

RM: Um, did you have any experiences with the engineers yourself? Were there any devices that you, um, used or tried to use to teach or was it really just technique based?

VT: Um, yeah, at that point, uh, at that point, I hadn't really gotten into, I don't think I even had my adaptive recorders then. [Hmm, yeah]. Um, I might have had that brace at that point but I didn't really, I didn't really talk to the engineers about my own personal, [yeah, sure], music-making. Um, also, I have never used a prosthetic. [No]. Um, I have enough of a hand that I never needed it or could really have one that [sure, yeah], that would be better than my hand, um, yeah.

RM: Nah, well, that makes sense, you know, because usually with the prosthetics, [yeah], it's, er, a whole hand or, you know, there's no digits at all I've found. [Right]. Yeah, and then there's the interesting thing of, um, some as, as you say with a whole arm don't want to use a prosthetic because it gets in the way and they resort to, [yeah], using their feet, which is much easier, [yeah], to build dexterity, um, in. And then there's some who because say it's below the elbow, um, [yeah], feel they need a prosthetic because they have enough of an arm and it's essentially a hand, I suppose. So, there, there's the, that middle ground, you know, that ground of, [yeah, exactly], you know, do I need this prosthetic or not? But, yeah... yeah.

VT: Um, I, I'm also curious. What other musicians in the United States have you talked to is there, can I pass on any more names, are you looking for more, [um, I'm], any more people?

RM: I'm, I'm nearly, um, towards the end of the, er, interview process because I've done, [oh, great], a few before. Yeah, but, um, yeah, no, no, if, I mean even in emails if you can give me some names at some point, [yeah, sure], er, if you're comfortable to. Um, yeah because I've, I've done some organisation stuff, I've done a few musicians, um, and I'm sort of looking at the, there's a music education hub in the UK, um, that doesn't look at disability; that has disability as like a subset of it. So, I'm looking more broadly as well and seeing how, for example, say if OHMI did something education-based, how a music education hub that covers the UK, how they could help and maybe, [yeah], their, sort of their knowledge of these things because it does, again as sort of another disconnect there. [Yeah]. Um, and so, yeah, that's coming sort of from the top-down rather than the ground-up, I suppose, in that respect, yeah. [Yeah, which, it makes sense though]. Hmm, yeah, thank you, yeah. Um, but, yeah, as I say, I've pretty much talked to most of the musicians I've wanted to, um, yeah, [they?] have(?) been very good, yeah. Um, yeah, so, as I said, er, in the emails, I'll send, um, the parts from this, er, interview, obviously the transcription that I use in the thesis. Um, and at that stage, it will just be you saying: 'yes, it's okay to use all of this', or if there's a certain passage, [great], that you want changed or edited in any way, er, just let me know. [Thank you. I really appreciated that]. That's alright. Yeah, um, and even if there's something that you want taken out, you don't need to give me a reason for it, just tell me which part you want me to take out and I'll, I'll do that for you. Um, yeah, no, it's been great. Thank you very much, um...

VT: You're very welcome.

RM: Yeah, um, yeah, so, I'll, I'll, I don't know when that will be because it's all taken a long time but it's probably at least, [yeah], sort of 6-12 months. Um, but yeah, I, I'll, as I say keep you posted on everything that's happening and yeah, if, if...

VT: And yeah, if there's anything else that you think of or anything else that, er, or if you think of another question or whatever, just let me know and I will be happy to help out.

RM: Okay, great. That's brilliant. Okay, alright, enjoy the rest of your day, Valerie and thank you...

VT: Thank you. You too.

RM: Thank you, yeah, thank you for your time. Thank you, bye bye.

VT: Bye.

Terminates at 01:01:25.

Appendix 13

Interview commences at 04:06

RM: Hi.

CM: Hi.

RM: Hello. Hi Carien. How are you?

CM: Alright. Nice to meet you.

RM: Yeah, you too. Likewise. Um, yeah. Thank you so much for taking time out to do this interview. Um, do you have any questions or comments before we start at all or?

CM: Um [Long pause], just interested really in what you're, you, you're, what you do. But I think, you know, we'll come, we'll, we'll talk about stuff as we go along, [Yeah], I, I imagine. [Sure, yeah]. And I just wanted to apologise for having been so difficult to, [Oh, no, it's fine], get around [to responding]. [Laughs].

RM: No, no, honestly, you've done very well compared to a lot of people who would [not respond]. [**Right**]. At least you contacted me; that's the main thing. It doesn't really matter, timescale wise. No, it, it's all been fine. Thank you. Um, [**Yeah**]. So, perhaps to begin would you, um, just for the record, state your name and give a brief description of who you are and what you do, I suppose?

CM: Yeah, um, My name is Carien Meijer. I'm the Chief Executive of Drake Music and have been since, um, 2006. Um, anything else?

RM: Um, no, that's fine, no. I mean if you wanna go into the role at all, but it doesn't really matter?

CM: Ah, God. How long have you got? [Laughs, Yeah]. So, you know, there, there's what it says on the tin. [Yeah]. Or on the job description. And that's, and that doesn't always reflect. It, you know, it, it's. Sorry about the background noise. [No worries]. There's a lot of noise just outside. [That's fine]. Is that bothering you? [No, it's fine, honestly. Okay]. Um, really, a bit of everything. [Okay]. Um, because we're a small orga[isation], we're [a] relatively small organisation. [Yeah, sure]. Er, so, er, as, as, as well as focusing on the kind of strategic development and, you know, keeping an eye on, on, on finance and, you know, stakeholder management; I get involved in lots of the day-to-day stuff, [Yeah, sure], as well. And kind of have developed Drake Music over the years from, you know, it's turned into a very different organisation several times maybe since I've joined. So, er, so, yeah. [That's great. That's fine. Thank you]. There's a lot to say. [Laughs]. [Yeah. No worries, no worries]. I'll keep it like that. [Okay. Thank you].

RM: Um, so, I, I suppose my first, um, main topic was, er, going to be about funding. Um, probably first and foremost, um, what is your primary funding source?

CM: Er, the Arts Council. [**Okay**]. So, we get funding from Arts Council England. Core[?] funded. We're what's called an NPO: National Portfolio Organisation [**Yeah**]. Um, and, er, and get core funding of just under £200,000-a-year [**Yeah**]. And that's usually for three or four-year period. [**Right, sure**]. Um, and then, yeah, so, but, our, our main kind of income tends to be from trusts and foundations, in addition to Arts Council and Youth Music is also a major funder.

RM: Um, sure. Um, so, do they have expectations for what you do, I suppose. So, there would be, I mean, when you say the three- or four-years plan, is it like a plan, I suppose?

CM: For Arts Council, yeah, you know, well, yes, they do. I mean, pretty much all funders do. [**Yeah**]. Uh, the, with, with the Arts Council, their funding is primarily for, what they call, kind of the core, the running of the organisation, [**Yeah**], so, to cover salaries and, you know, office space and, you know, all of our kind of, um, core costs. But, there is an expectation and we do have to apply every sort of three to four years for funding and lay out what our plans are, what our strategic objectives are, you know, where, you know, where our focus is and how we meet, or most importantly I think for the Arts Council, how we meet *their* strategic objectives, how we deliver on *their* strategic plan.

RM: Sure, yeah. Um, so, with the, how the funding, um, how is it distributed? Maybe, who benefits, er, maybe, I don't know if you can really do a percentage divide but maybe who gets what or what does it go towards, I suppose?

CM: [Long pause]. Um, well, there are different ways, I guess, of looking at this. But there's the, so, a, a, a percentage, ah, I don't know this. A percentage of our funding goes to the organisation; our running costs. And then there's, of course, quite a big percentage that goes on the delivery of our projects and programs. And those projects and programs go, you know, that, that can range from working in, um, special and mainstream schools, right through to commissioning artists to make new work or designing and building new instruments. So, um, we *rarely* give money directly to an individual. Although it does happen, particularly when we commission somebody to make a piece of work, that's...

[Yeah]. But, um, but, on the whole, it goes to, to kind of funding projects.

RM: Sure. That was great. Thank you. Um, so, with, um, other organisations, have they collaborated in any way, on any projects that you've done? Are there, are there any, sort of notable examples or sort of that...?

CM: Yeah, I mean, er, we work, uh, we haven't counted them this year, but we, we tend to work in partnership between, with between sort of 40 to 60 organisations a year. [**Yeah**]. So, and those partnerships can be very small or kind of ones that stretch over several years. Er, at the, right now, we're, or have we, we have, have, we have been working with the, um, London Philharmonic Orchestra on a partnership project, and that's actually been for many years. We've just started a new partnership project with music in prisons or arling trailer trucks(?), they're called. Uh, it's a, we, we're working in partnership with music education hubs. We're working in partnership with other arts organisations. So, how, it's a, it's a

real mixture. [**Um, sure**]. So, back in the day, our reach would be a lot smaller and more limited if we didn't work in partnerships, [**Sure**], with some of these organisations.

RM: Yeah. Um, so, would there also be partnerships with people from other fields, so, such as therapists, not just music therapists, maybe like occupational therapists and physical therapists or, um, particularly with what I'm looking at with limb difference, [**Yeah**], I'm looking at prosthetists or something like that or hospital settings. Would there be any partnerships with any settings like that?

CM: Right. We have done, actually very, um, very rarely, to be honest. So, er, we have done some work in hospital settings. I think there's scope for doing more. It's not an area where we've really put a lot of our, um, focus. And that may be partly because we don't have those networks or the expertise internally. [**Sure**]. So, I think it sometimes depends on, you know, who brings what, [**Sure**], to, to any organisation. Um, but, so, I think there's scope for more. In terms of working with therapists, we don't, we do do it, but not very often. [**Sure**, **yeah**, **that's fine**]. And I think, you know, there is, sometimes externally, um, an expectation that we provide music therapy, which we don't. And are, um, are that, my, my team is, you know, we've got all kinds of workshop leaders, musicians and so on and so forth. Some of them are, happen to train as, as therapists. But our work, although it has therapeutic benefits, we're, it, it's, it has very diff[erent], it, it's about access to music-making. [**Yeah**, **sure**]. It's slightly different, [**Yeah**, **yeah**], you know, focus is assisted(?).

RM: Yeah, I, thank you, yeah. Um, so, has any of the, er, collaborations been international or is it all UK-based?

CM: Yeah, er, actually today, er, er, earlier this afternoon I had a meeting about an international; we've been working, an, an international project. We, we've been working in partnership, particularly with British(?) Council in Japan, and have done so since 2017/2018. And are working closely with Tokyo Symphony Orchestra and Persake(?) City Council and British Council Japan. And we've also done work in, in, in other, um, countries. But the biggest partnership, the most, the sort of ongoing partnership is with Japan.

RM: Yeah, okay, sure. Um, so I'll move on a bit, er, on the other side. Is, um, a key to a lot of your collaborations that they're localised so you can get the expertise to these areas where they're needed rather than being distanced?

CM: [Long pause]. Yes. Although that changed quite, [Yeah], significantly during Covid. When, you know, we had to rapidly, like everybody else, move our work online. [Sure, yeah]. So, it didn't really matter where you were based then, so... Er, but we have, er, historically, kind of have a, and still do, have a team in London and our main offices in London, er, and a team in Bristol and the South West, and these are big words, *small teams*, [Sure], in, er, in Manchester and the North West. So, that's kind of, we, and then, you know, we work, in, in different parts of the country. So, where we don't say, if there is an area where we would like to work but we don't have the network, nor the expertise, nor anyone locally, then that'll, that, that becomes an immediate(?) barrier. And, and something where, you know, we, we would need to put a lot of time and resources to develop that.

RM: Sure, yeah, that's great. Thank you. Um, so, on the website, it says, um, that there's been '100-000 music-making opportunities for over 1,000 disabled people', has that grown since you've been in charge; did, did it start slow and has gradually got pace or has it...?

CM: Many(?). I mean, it, it's really. I always have some difficulty with the numbers, [Sure, yeah], so, you know, so, it's quite a big thing to say, you know, the, the statement we make on the, on the website. I'm not saying it's wrong. [Yeah]. I think it's, you know, how often are those opportunities? And how often is it the, the same people that..., you know? Just to me, you know. Because a lot of our work, actually, is in small groups, and one-on-one, and, and takes a lot of time to develop. Of course, because we, because of the partnership work and because we also train up other people in organisations, to do the kind of work that we do, [Yeah], our, our reach becomes wider(?), and that impact, you know, grows. Um, when I started, Drake Music was, when I started with Drake Music, Drake Music had been, been around for a long time by then, but it was very different organisation. At the time, to be fair, we, I think we, if, if we reached about 40 people, I'm being generous. It was, um, but that, yeah, but that said more about where Drake Music was at than, [Sure], there not being the need. [Yeah, sure]. Um, so, um, I mean it has grown. I think what the, the, the, the, we always need to be quite careful, in terms of where we put the emphasis on, in terms of, you know, the numbers of people we reach or the quality of the experience, [Yeah, sure], or, and how you can ensure that you retain that quality, even if you want to reach more people, and how do you do that in a, in a safe and, um, cer[tain], and an, an appropriate way? [Sure]. It's... [Yeah]. Yeah. [Okay].

RM: Yeah. Um, so, another, um, area I was looking at as well was the DMLab from 2010. Could you perhaps describe how that's changed since it began to maybe now? [**DMLab**]. Yes. [**Yeah**]. yeah. [**Yeah**].

CM: So, yeah. So, that's, I mean it's re[ally], that's a really interesting area of our work. Um, in, I think it was a little bit after 20[10]. It was in 2011/2012 that, at least we decided to, [long pause], to call that area of work 'DMLab'. [Yeah]. And to really focus on bringing together: er, disabled musicians; technologists; coders; hackers; you know, instrument designers; makers; thinkers; whoever, and, and actually kind of look at the idea of hackathons at work sort of, they were probably not new at the time; but to us, they were fairly new. And certainly, it then, it informed our way of thinking and working in that we said: 'Okay, right. If these hackathons are happening all over the place, how can we do something similar, [long pause], but in a, but really focusing on accessible designing, accessible instruments? And, you know, so, so, what do we need to do to make a hackathon relevant and worthwhile to the communities we work with?' And that started in a really kind of small way by us just testing, simply running our first hackathon, which I think was in 2012 or something or 2013, I can't quite remember. And out of that grew a community that we call 'DMLab', um, and particularly in London and in Manchester that was, it's changed a little bit, but that was a, a, a kind of, a, a group of disabled musicians and technologists and others, they(?) would kind of come together to solve, um, not problems, to solve, to look at challenges, you know. So, so, we would have say a musician say: 'Well, you know, I've always, you know, wanted a guitar but none of the instruments out there are accessible to me, and I need a concert grade instrument.' This happened in the case, you may have seen this, in the case of John Kelly, [Yeah], and the Kellycaster. Um, and we went: 'Okay, well,

let's see what we can do'. [Hmm, sure]. And, and I think having that approach, so, where we said: 'It, it's a, we're, we're gonna test it, we're gonna try it, and we're gonna see what happens.' So, it wasn't, it wasn't as if I had a really clear plan, in terms of how that would develop, and we didn't quite know where that was gonna take us. And I think that was the strength of it(?). Um, we also, so, we, we, we've got, and, and that has been started(?) with new instruments or different ways of working and, er, and, and also various prototypes and, and what have you. But the, it is still a very important part of Drake Music is, is DMLab and all that, that work around, er, er, designing and making instruments that, and the coproduction, co-creation with, with artists and technologists. [Yeah]. Uh, funding it is quite hard; it's not straightforward. So, at the moment, it is quite quiet in, in, in that side of our work. [Sure]. Um, yeah.

RM: Yeah, that's great. Thank you. Um, so, with, er, some of the musicians and the organisations I've come across, there seems to be 'the emphasis is on the prototype' but it's also, whether the prototype should be individualised for the musician, the one musician, or whether it should be aimed, so, maybe for mass production of a certain instrument or device. Is it really a case-by-case basis when, er, Drake Music's making these things?

CM: Yes and, but we haven't got, it is. And I think, for us, it is very much disabled artist or musician-led. [Yeah]. And, and, however, having said that, some of the prototypes I think are probably designer and technologist-led, you know, [Um, yeah], so, particularly the earlier ones. Um, [long pause], the, getting to a proof of concept or prototype stage is not the, the difficult thing; it's going from prototype to, uh, an instrument that, [Yeah], somebody could, you know, use on a day-to-day basis. [Yeah]. Um, And then, the challenge of then potentially, because what we have always said is: 'Okay, we've got the Kellycaster. Now we want to have hundreds or thousands of educational Kellycasters, [Yeah], so, we could use in schools, [Yeah], for example.' So, you then move away a little bit from it being designed specifically, er, with one particular, you know, musician in mind and his [Kelly's] particular kind of musical and access requirements. We have never done that! We've, we still, although we talk about it, we still don't have the educational version of the Kellycaster. [Yeah]. Not do we, nor do we, um, er, we've never, and in a sense never wanted to, go into: 'Okay, we're now going to manufacture, or we're, you know, loads of, you know, instruments'. [Sure, yeah]. That's just not, um, where, because we're so small, we cannot put, that's not where we can put our energy or our resources because they're very limited. [Yeah]. However, I still think that's an area that needs to be explored further, [Yeah, okay, **good**], definitely.

RM: Thank you, yeah. Um, so, I'm gonna move on now to the actual, er, the headquarters, the office space. [**Yeah**]. Has that changed since you got there in 2006? Is it more office based or are there, er, spaces for music? Maybe, how, how that's changed?

CM: Yeah, well. When I joined, we were based in, um, South London at the Albany(?) and had primarily office spaces, actually, but it didn't quite work anymore for what we needed. And then we moved to Rich Mix in, er, East London and it was, it was, and has been, over all those years, primarily, um, office, you know, work space-focused. [Yeah]. And I had always wanted that not to be the case, [Yeah], but never succeeded. [Laughs, sure]. So, I always have big plans or had big plans for, you know, wanting spaces to be used by artists and

musicians to, to, you know, come in and to, you know, and it does happen, but it's primarily office kind of, you know, stood(?) the, kind of, the work that happens in the background. [Yeah, sure]. Our [long pause] ideal and, and actually conversations we've had a lot over the past couple of years at board level is to, and it, and I don't know if it would ever happen, is to have a, a multi-purpose space somewhere in the country that would be workshop space, accessible, um, DMLab or, [Yeah, yeah], hacker spaces, you know, hacker maker spaces, [Yeah], to find somewhere that's accessible and safe to, you know, where you can make and design an instrument simply doesn't exist in the way that we would need it. [Yeah]. So, we, so, I wanted something where we could do all of that and the office space work. [Yeah]. And hopefully, one day that will happen but it still hasn't. Now, we, we've also been based at the community centre in East [London], or next door to a community centre where we moved out of Rich Mix(?), then two years ago, we moved back to Rich Mix, and then, the pandemic happened, [Yeah, yeah, sure], and we had to close the office. And we've never really recovered from that. So, or, no, no, our, our office is no longer that hub where so much, you know, even though it was primarily ran through the, the, kind of, the admin and the organisational side of things, people, you know, a lot of our musicians would come in and, you know, pick up instruments or tech or, you know, come in for meetings; at lot of this is gone. [Yeah]. So, there's a lot more remote working or hybrid working.

RM: Sure, thank you. So, was that, sort of, at that, because I've, saw on the website about the Accessible Musical Instrument Collection. Is that what that was aiming towards? And as that, is that gone ahead or is it...

CM: Well, yes, but it, but then with the pandemic, er, all of that had to stop. So, er, the idea was, and still is, that we get to a stage that people could come in and look at the collection, however small or big it is, and it would ini[tally], it, it would start out, and did start out in our office. Um, but eventually be somewhere [long pause] different, [Yeah], in this ideal space that I always had in mind. But where you could come and try out instruments and see if there's anything there and, you know, that would, you know, fit whatever access requirements you might have or interests you might have musically. Um, [long pause], that, all of that stopped, um, in March 2020, when we were just beginning to build it. And, so, we're still going to develop it and get it up and running but I would say we're now about at least two years behind, [Right], on balance(?), [Sure], yeah, [Yeah].

RM: So, um, with that being a physical space, would there also be room for sort of archiving information from that, [**Yeah**], collection online? Yeah, [**Yeah**], yeah.

CM: Yeah, that's the idea. We want to digitise it and archive and, you know, I've, you know, now I'm talking to you and go: 'Oh God, this is all so interesting and exciting'. It's that, kind of, but all of that took a, [**Yeah**], yeah, a, a real hit. And we, but that is the intention.

RM: Sure, yeah. Um, cos with something like that as well, I'd, I've been looking at major manufacturers as well, you know, the, so, like Yamaha, just for example say. Um, have, have any sort of major manufacturers allowed you to use their equipment for any technology whatsoever?

CM: We get, yeah, we get given quite a bit of stuff. [**Yeah**]. And, and, yeah, we do. [**Yeah**]. Or, or we'll get things; we get given quite a bit, actually. Um, and there's a real interest on the, um, on the part of some companies; tech companies to, for us to look at their products and, and suggest how it could be made more accessible, for example. [**Yeah**]. So, again, that's a whole area where that we begun, where we began to develop and build, kind of, partnerships and potential for, kind of, future collaborative incentives. All of that, kind of, began when us, us taking a real hit during our time out, [**Sure**], (?). [**Thank you**].

RM: Um, also with the, like I was talking about the archiving stuff, I've seen there's a lot of resources on websites such as tech possibilities, things for teaching and education, [Yeah], instrumental stuff. Is that able to expand beyond [the] website at all? Or is it just information on, in this one place?

CM: It, it could be expanded. But yeah, I mean, we, it, we would, we are an organisation now of this, you know, any small organisation will say this, we're very, very underresourced. [Yeah]. So, it, you know, we would need, and we don't always have sufficient expertise in-house. So, there is a lot, there is huge scope to take it beyond what, what, where it is and what it is, [Sure], now, [Yeah]. But it'll happen, [Yeah], um, here's another thing. But I think it should, [Yeah], I think, you know, much more widely available. [Um, yeah]. Yeah.

RM: That, kind of, leads me to my resear[ch], I suppose, the culmination of my research is the idea of a centralised knowledge base. So, for, [Yeah], teaching, technology, instruments, just bring information, [Yeah], on musicians. [Yeah]. Um, I suppose it's a silly question, but would you advocate for a centralised knowledge base for these things? [Laughs]. Yeah.

CM: [Laughs]. Yeah, I think I would, you know. I think that, uh, obviously would make an awful lot of sense. The, the one thing that occurs to me, and I'm not sure how relevant that(?) is, is to make sure that the context in which those resources were created is understood, [Yeah], or that there is some, that sounds really vague. Or, or whether there's a collective understanding, uh, you, how the, these resources are created and how the knowledge base is, you know, who's, who's got the, um, who holds it? [Sure, yeah]. And whether that's disabled-led. I think that's again something that we can talk about a lot. Sometimes we find, and I'm going off-topic a little bit, but that don't quite align with other organisations or people. And then it becomes quite tricky to bring lots of things together. [Yeah]. Or unless you're clear on what basis you're doing it. [Yeah].

RM: Well, it, it would really be, it is the bringing people together cos you, the, there just seems to be a disconnect between musicians doing it and having great ideas, but on their own and it's not being spread to some, someone, like a guitarist playing with their feet is kept within that person playing with their feet, where it could benefit other people, other musicians. [**Yeah**]. So, I think it's a, [**Definitely**], you're having to bring organisations and musicians together, not just, um, you know, an in-person collaboration but also an online, and just, [**Yeah**], just sharing of knowledge, [**Yeah**], for the benefit of everyone really. That's it. [**Definitely**]. Yeah, yeah. Um, would there be any, sort of, other, er, things I need to look out for you think with a, something like that, a knowledge base of that type?

CM: [Long pause]. Uh, I haven't given that enough thought. I think where we see a real need is, kind of, what you just described. But it's a, it's a roundness(?) or that there, it's also serves as a connector of people. [**Yeah**]. And a sharing, so that the knowledge, it, what you were saying there. So, that it's shared and it's un, you know, and is, and is very, very accessible. [**Yeah**]. So, there are no barriers to accessing it. So, those sorts of things that I think are really key where there's a real appetite, which we've found particularly in our DMLabs. Um, and, and, and even more so perhaps during the pandemic that there was a real, um, appetite for coming together and sharing of, you know, 'this (?) really works for me, what do you think?' Or 'I'm really, I'm looking for that but I don't know where to go?' [**Yeah**]. Or where someone would come and say: 'I've designed this? What do you think?' Or, you know, and, and that was, that, that's a, kind of, what informal sharing of knowledge and, and, and so on. But it also served to connect people and to, kind of, go: 'Oh, okay. So, people are thinking about this, or this is being done, or this does already exist, [**Yeah**], and we could potentially build on that'.

RM: Um, that's great. Thank you. Um, so, that's all the main questions I have. So, um, if there's anything you want to ask me or any comments you have at all. Um, I mean I can run you through what I'm doing for my research if you'd like, er, but it's up to you.

CM: Yeah. Where, um, what made you focus on, what, what drove you to, kind of, focus on this area?

RM: I did, um, an undergraduate dissertation on how disabled musicians, popular disabled musicians make music and I was very interested in the, the various ways of, for instance, adapting the instrument or making the device to play an instrument or adapting themselves to the instrument without any modification. [Yeah]. Um, and I just thought that could, the, the potential, you know, there's so much potential there. Um, and then, it led, er, I was, I was doing Music Composition degree, so I, so I did a Masters in Composition as well. But when I got to PhD, um, I was gonna look into the building, technology side, um, [Yeah], but I just found, well, I, I don't have the expertise, to be honest. But I, I think I work better in a theoretical way and then, to then be practical rather than practical from the start, I suppose. Um, and then, the, I thought I'd focus on one disability in particular, just cos it's a PhD and it's a study and you have to be quite limited in the way you think, [Yeah], cos it, it's 80,000 words but that's not a lot if you, er, take it in. So, I looked at the, um, limb differences, the absent limb cos I always found the prosthetics quite interesting with that as an extra element of what I've been looking at as well. [Yeah]. Um, and then, yeah, this really led to, so, my chapters are about popular musicians, um, specific examples in popular music and looking at the various ways, that's, sort of, a foundation. And then, that's leading into, sort of, lesser-known musicians and how they, um, go about playing and also the idea of, you know, what's musicianship? Is it control, you know, expression? Or is it just being able to play something? As I've said(?), there's a lot of information and research, [Yeah], on that. And then, moving on to the organisational support, so, obviously, what you're doing and other, um, organisations as well. And then, also how individuals have found their own personal experiences of organisational support. [Yeah]. Um, like you were talking with under-resources and under-funding, that's, sort of, been the main, um, topic. And then, obviously, with, it all culminates with the conclusion, the advocacy side, and this, [Yes], centralised knowledge base. So, that is the thesis in, um, [Yeah], I, I have the challenge of

talking about my thesis in three minutes. So, that's basically what I'd say for that. [Laughs]. Yeah, that's pretty much it.

CM: Yeah, brilliant, yeah. So, and, and so, you've talked to, kind of, similar organisations in, in this field as well?

RM: Yeah, er, the main one was, er, OHMI because obviously they're, [Yeah], directly, [They're, yeah], with, um, [Yeah], absent, limb differences and absent limbs, [Yeah]. Um, I've also talked to Can-Do Musos in America cos they deal primarily with professional musicians, um, [Yeah], so, I wanted that side as well because you've got the different level set, you know, skill sets, I suppose. And then the different genres of music because I'm finding that, especially with OHMI with the resources they have, it's very classically-driven or genre-based, [Yeah, yeah], and it, it's, um, you've got the problem there of; that's obviously, a genre dealing in perfection already and then, you've got the disability, disability on top. So, I'm looking to bring it more towards accessibility and, you know, popular musician, you know, the, the way of getting in there, I suppose. Um, [Yeah], yeah, they're the main three, I suppose. And then there's, um, sort of individuals who run camps and things like that. And there, you know, it's only on a small level; they've collaborated with bigger, er, organisations, more to do with, er, [long pause], resources for everyday activities, for example. And then, translating that to music, and then how music can translate that to [everyday]. So, there, you're having, that's where the therapy side came in as well at that point. So, it's how to connect these different groups in the best way, I suppose. And that's where the knowledge base again comes in; trying to bring in people from other fields. Um, and the difficulties of doing that, I suppose, but, it'd be worthwhile.

CM: Yeah, and I think, you know, there is, I think one of the, the issues, um, or, or, and this is not I think, it's not uncommon at all, is the, kind of, the lack of signposting, [Yeah], or connect people up with other, um, with peers or with other organisations, [Yeah], or, you know, there, there's a lot in terms of that, that doesn't really exist enough.

RM: Yeah, yeah, sure. No, that's great. Thank you. Um, so, if there's anything else you wanna talk about or comment on, um, I, I'll let you go cos I realise you, um, you know, time-conscious, sort of thing.

CM: Yeah, I've a, yeah, no, well, unless there's anything else you'd like to ask me. I mean, I, I think, you know, this sounds, or I know it doesn't just sound, it, it's a really important and interesting, [Yeah, thank you. Yeah], um, vital area of research. [Yeah, sure, yeah. Thank you. Yeah]. Yeah.

RM: I mean there might be, maybe if I've just got one question in the future, [**Yeah**], I might just email it to you or something and just, [**Yeah**], maybe, if, if I need like a sentence or something or, you know, a quote that would be useful, that might be something. But, at the moment, [**Yeah**], I've gone through pretty much everything that I wanted to ask. So, thank you. Thanks a lot for that.

CM: Okay, okay. Well, good luck with it.

RM: Yeah, thank you. Cheers, yeah.

CM: Yeah, yeah. If there's anything, you know, just drop me a line and then, eventually, as you know, you'll get an answer. [**Yeah, okay, great**]. [Inaudible] [Laughs].

RM: Yeah, no worries. That's fine.

CM: Okay, take care.

RM: Thank you, bye.

CM: Bye.

Interview terminates at 40:11.

Appendix 14

Hi Yogesh, (Yogesh Dattani)

Thanks for your response. To enable us to proceed, I am attaching a Participant Information Sheet containing background on my research and details of the process for your information. Additionally, I have included a Consent Form, which I need to be signed and returned in order for me to use your responses in my thesis.

Below are the three questions I would like answered:

- 1. Could you give a brief overview of the infrastructure of your hub? The lead organisation consists of 1 head of service, 2 deputies (both 0.5fte), 1 business manager, 2.5 admin staff, circa 45 teachers. The governance structure comprises a range of stakeholders.
- 2. Could you provide examples of collaborations your hub has made/is making with other organisations/hubs/people to assist disabled musicians? While Equity, Diversity and Inclusion is an important part of what we do (I am the EDI Lead for Music Mark), we have not collaborated with other hubs in this regard. We encourage our partner organisations to work with children and young people with special educational needs and disabilities (SEND). For example, one local opera company is currently working with children with SEND in mainstream schools. We have 6 special schools and our SEND Music Consultant supports each one on a rota basis and, in addition to this, we work with a range of partners to further enrich our offer, for example, with Live Music Now and the Orchestra of the Age of Enlightenment.
- 3. If a disabled musician approaches your hub, what information/resources/provisions/advice could your hub provide to suit their needs?
 - In my 22 years at Ealing Music Service (as head of service since January 2004), I don't recall any disabled musician having approached the music hub. I would like to become more effective and seeking out disabled musicians in needs of support. There was one occasion when one of my senior colleagues faced a situation in which one of her violin pupils had the last digit of their thumb missing and, therefore, could not defy gravity and hold the bow up. I contacted The OHMI Trust who promptly sent me pieces of equipment that would compensate for the missing digit and the child was able to participate in violin lessons.

With regards to point 5 of the Consent Form, please could you state whether you would like all references to the hub and/or yourself in my thesis to remain anonymous or for yourself and/or the hub to be named. I am happy for me and the Ealing Music Partnership to be named.

Appendix 15

1. Could you give a brief overview of the infrastructure of your hub?

A brief overview can be found here About us - Devon and Torbay Music Education Hubs

We are a commissioning model, so we work with and support other partners, schools, teachers, self-employed Visiting Music Teachers (VMTs) etc, rather than directly employing or contracting people as with the old Music Service Model.

- 2. Could you provide examples of collaborations your hub has made/is making with other organisations/hubs/people to assist disabled musicians?
 - Current project: In collaboration with the SEND support team, Devon County Council, aimed at children with physical disabilities in mainstream education. So far this project has involved one day practical group music making workshops in different areas of Devon. Individual participants have availed of the offer of follow-up visits by me to address compatibility and accessibility of instruments. Follow-up work will also aim to work with VMTs to enable them to give effective and meaningful instrumental lessons. Next stages include creating regular accessible ensemble playing opportunities for children with physical disabilities, working with existing Hub funded ensembles to help them remove barriers and provide access, and support schools to ensure that music opportunities are equitable and accessible.
 - Also in collaboration with SEND Services DCC, a one day music and dance workshop in June 2023, for children with hearing impairment.
 - We are in the process of introducing a system to enable / require schools to identify children with physical disabilities in classes for whom class sets of instruments have been hired from the Hub. This includes children who may not be on the SEND register. One of the Hub Team can then, if necessary, carry out an assessment to ensure that the instrument is compatible in its standard form, and if not, adapt or source an appropriate instrument and support the teacher to ensure that the child has an equitable and meaningful experience.
 - The Hub funds and supports a number of Hub Funded Partners which can call on additional support in ensuring that activities are accessible to children with disabilities. Hub funded opportunities area <u>County groups - Devon and</u> <u>Torbay Music Education Hubs</u> and <u>Making music in your area - Devon and</u> <u>Torbay Music Education Hubs</u>
- 3. If a disabled musician approaches your hub, what information/resources/provisions/advice could your hub provide to suit their needs?

They would be offered bespoke support needed to address unsuitability of the standard provision, e.g.

- Signposting to a wide range of musical opportunities, and a wide range of hire instruments.
- Adapted or alternative instruments, adapted in our workshops by one of our technicians, or hire from the OHMI Trust, <u>Home (ohmi.org.uk)</u>
- Support for their teachers, school, and local Hub funded opportunity in meeting the needs of the child.

Appendix 16

- Could you give a brief overview of the infrastructure of your hub?
- I am not sure what exactly you mean by Hwb. I run music therapy sessions for children across [REDACTED] and [REDACTED]. I work for 2 Music Services – [REDACTED] and [REDACTED]. I work as self-employed. There are [REDACTED] music therapists working for [REDACTED] and [REDACTED] working for [REDACTED].
- In [REDACTED] I work through [REDACTED] Government Funding [REDACTED] initiatives in some of the most socio-econmoically deprived areas.
- Could you provide examples of collaborations your hub has made/is making with other organisations/hubs/people to assist disabled musicians?
- As I am a music therapist, clinical gaols and aims developed in collaboration with the schools. For example, I work with children with ASD. They have specific treatment plans which through planning and evaluation with the relevant staff, they are unique and bespoke. The range of needs for the children is diverse, yet all have access to the sessions, sometimes with adult support. The schools in which I work are DDA compliant so all children are able to access support.
- [REDACTED] has worked with local Autism Charities, Women's Refuges and Special Schools within [REDACTED] to deliver music therapy and peripatetic lessons. As I do not deliver lessons in these schools, I am unable to answer in reference to lessons in this context.
- I can say that all concerts held by [REDACTED] have disabled access, adult support etc to enable them to fully engage in showcases.
- [REDACTED] is on two floors. There is ramp access to both floors, allowing inclusive access.
- If a disabled musician approaches your hub, what information/resources/provisions/advice could your hub provide to suit their needs?
- This is difficult for me to answer as I do not have a hub. I work independently around many schools. However, should a disabled person wish to have music therapy at [REDACTED], I can provide safe access, adapted instruments and a range of multisensory developing technology to allow improvisation, compositions, performance and enjoyment.