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Full and Equal Equality

Purpose: This commentary takes the article, Participation of adults with learning disabilities in the 2015 United Kingdom General Election, as a jumping-off point for considering the tension between the aim of full and equal equality for all people with disabilities as set out in the Convention on the Rights of Persons with Disabilities and more traditionally beliefs, that on occasion, it is necessary to deny the legal autonomy of men and women with intellectual disabilities in order to protect them.

Design: This issue is explored by reviewing the multiple and often conflicting ways in which disability and intellectual disability are conceptualised.

Findings: Given the multiple and contradictory ways in which both disability and intellectual disability are understood, any discussion of the rights of persons with disabilities is going to be highly problematic.

Originality: Equal recognition before the law and the presumption that all persons with intellectual disabilities can – with support – make autonomous could be treated as an empirical question.

Men and women labelled as intellectually disabled are often denied opportunities to make decisions concerning their own welfare because others deem them unable to reason and act independently. Moreover, such beliefs, that have legitimated state-sanctioned segregation (Rolph, et al, 2005), sterilisation (Servais, et al 2004), and murder (Burleigh, 1994). Even in an enlightened era, such as ours, a persistent belief in the incompetence of people with intellectual disabilities means that their rights as citizens are often ignored (http://www.mdac.info/). The United Nation's *Convention on the Rights of Persons with Disabilities* (CRPD) seeks to address such discrimination by aiming to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities" (Article 1). However, even among States ratifying the CRPD, and which are otherwise committed to the equality of people with disabilities, men and women with mental disabilities may still be denied the right to self-determination. In England, for example, the rights of people with intellectual disabilities (referred to as learning disabilities) are asserted in *Valuing People: a strategy for learning disability for the 21st century* (Department of Health, 2001) and protected in the *Equality Act 2010,* which prohibits discrimination on grounds of disability. Yet, a separate piece of legislation, the *Mental Capacity Act (England and Wales) 2005* contains provisions for making decisions on behalf of persons who as a result of a "mental disability" – an impairment of, or a disturbance in the functioning of the mind, or the brain (s.2) – are judged to lack the capacity to make specific decisions. This *Act* was drafted to protect people who, lacking capacity as a consequence of a mental disability, might refuse life-saving medical treatment where is a good chance of survival; or dispose of assets without due regard to their value. Any decisions made on such a person's behalf must, the *Act* stipulates, be made in the "best interests" of the person lacking capacity (s.1). The power to deny legal capacity where it is judged that a person with a mental disability lacks the functional capacity to make one or more autonomous decisions, can however be viewed as discriminatory, and as a contravention of the CRPD. Moreover, it is argued that the loss of such a fundamental human right as legal capacity leads precipitously to the loss of all human rights, including the right to life (Bach, 2017).

There is, consequently, something of a controversy between those allying themselves to the CRPD's goal of full and equal equality, and those who believe there are specific occasions where it is advisable to restrict the legal capacity of men and women with mental disabilities so as to protect them from possible harm.

Much has been written about this controversy, with efforts focused upon the needs of unconscious patients (so called hard cases); bringing national legislation into line with the CRPD (Martin, et al 2014); the practicalities of supporting people with mental impairments to make and communicate their own decisions (Despott, 2017), and the compatibility of legal autonomy with supported decision-making (Morrissey, 2012). With the purpose of shedding new light on what is increasingly becoming an intractable issue, I propose to take a brief tour through the ways in which *disability* and *intellectual disability* are conceptualised. In doing so, I hope to offer a productive way of understanding - but not necessarily solving – this controversy.

The Preamble to the CRPD, while asserting that disability is an evolving concept, offers the following definition: “disability is a hindrance to a person’s full and effective participation in society as a result of an interaction between a person’s impairments and attitudinal and environmental barriers”. In addition, Article 1, states that persons with disabilities are those with “long-term physical, mental, intellectual or sensory impairments”. The CRPD is based upon the premise that no matter the nature or severity of a person’s impairment, all people can - and should - enjoy full and equal equality. This includes legal capacity. The Committee responsible for the CRPD holds the view that all men and women with mental disabilities can make and communicate their own decisions, if they receive appropriate support (United Nations, 2014). The idea that a person’s legal capacity, including the right to exercise it, should be based upon a judgment of their mental capacity is categorically rejected. This is why Article 12 of the CRPD - *Equal Recognition Before the Law* - requires States to provide the support necessary to enable people to exercise their legal capacity (*para 3*), and that the support safeguards their rights, will, and preferences (*para 4*). It is the case however, that the CRPD’s definition of disability glosses over what some would consider a crucial feature of living with an intellectual disability. Namely, significant cognitive deficits (occurring in the developmental period) with respect to reasoning; problem solving; planning; abstract thinking; judgment; and learning (both academic and experiential), which impact adversely on a person’s ability to function (American Psychiatric Association, 2013). The impact of these cognitive deficits on a person’s ability to function, raises the question whether *all* people living with an intellectual impairment are able to make autonomous decisions, even when support is provided.

The CRPD draws inspiration from the social model of disability, a model that associates disability with discrimination and political action aimed at securing universal access through the removal of physical barriers and challenging prejudicial attitudes. While some proponents of the social model have stressed the importance of economic factors, especially employment opportunities (Barnes & Mercer, 2005), others have focused on the damaging psychological consequences of living in a society that values physical prowess and bodily perfection (Reeve, 2006). In either case, the social model is thought to have little purchase on the phenomena of intellectual disability. This is because, despite the fact that people labelled as intellectually disabled experience stigmatisation and violence (Quarmby, 2011), it is less clear how their mental impairments can be remedied through changes to the physical environment (Chappell, 1998). In addition, the social model is thought to be biased towards the experiences of males with static disabilities (Thomas, 2007) while having little to say concerning the embodied aspects of impairment (Hughes & Paterson, 1997). These deficiencies have prompted disability scholars to ask whether the social model – despite its political potency - offers a satisfactory account of disability (Shakespeare & Watson, 2001). In response, there are those who argue for a bio-psycho-social model of disability, believing that life with an impairment cannot be fully understood without acknowledging its bio-medical reality (Shakespeare, 2013). While others, in sharp contrast, assert that impairments – especially mental impairments - are socially constructed by "psy-professionals" to have the institutional authority to diagnose and label people's behaviour (Rapley, 2004).

Advocates of a bio-psycho-social model conceptualise disability as a multi-layered phenomenon that encompasses bodily impairment, individual and social psychology, in addition to the wider physical and social environment (Shakespeare, 2013). While there is something reasonable about this approach, it leads inexorably to the conclusion that there will be some people who, due to the severity of their impairment, and irrespective of the support they receive, will be unable to make and communicate autonomous decisions (Vehmas, 2008). However, while a bio-psycho-social model appears to offer a comprehensive understanding of disability, it is a model that gives no formal or systematic consideration to the causal significance, or weighting, of its constituent elements. Consequently, the bio-psycho-social model is perhaps less a model of disability and more a check-list of relevant matters (Burns, 2014). And as a list, there is a tendency towards a conceptual anarchy: researchers are free to choose what weighting to give the constituent elements (Ghaemi, 2009), and frequently disputing the relative significance of those elements (for a recent example of this see Shakespeare, et al 2017). Unsurprisingly, these disputes often turn on whether bio-medical diagnoses should be accepted at face value, or treated as social constructions (Pilgrim, 2015).

The social constructivists' critique of "intellectual disability", is particularly persuasive because intelligence is not observed directly, only inferred from performances on standardised tests of intelligence. Tests, which through a process of circular reasoning construct the very thing – intelligence – they purport to measure (Boyle, 1999), and use mathematical demarcations (standard deviations along a normal distribution curve) to distinguish between those with and without an intellectual disability (Jenkins, 1998). Moreover, authors of this stripe delight in highlighting that the criteria used to diagnose and then label an "intellectual disability" are in an almost constant state of flux (Rapley, 2004). Moreover, ethnographic studies have elegantly demonstrated that once a person is labelled as having an intellectual disability others will use that diagnosis to find further evidence – in the person's speech and behaviour - that s/he does indeed *have* an intellectual impairment (Rapley, 2004). All of which testifies to the social conventions necessary to construct the diagnosis and then label a person as intellectual disability. There is a danger, however, that by questioning the reality of intellectual disabilities the social constructivist critique loses sight of the functional deficits that medics are seeking to describe (Hacking, 1999), and furthermore, they could be inadvertently undermine the basis upon which this population is able to claim special disability-related rights (Vehmas & Watson, 2014). Moreover, the professionals responsible for developing the diagnostic category, intellectual disability, are fully aware that they are actively engaged in a process of social construction (Switzky & Greenspan, 2006).

The Handbook of Evidence-Based Practice in Intellectual and Developmental Disability offers a short history of how the diagnostic category "intellectual disability" has changed (Harris & Greenspan, 2016). This history, focused on the activities of the American Association of Intellectual and Developmental Disabilities (AAIDD), and beginning in 1961, charts the development of the three-prong definition of what was then known as "mental retardation": sub-average intellectual functioning originating during the developmental period and associated with impairments in adaptive behaviour. Although this history is a narrative of development and refinement, it nonetheless clearly shows the social pressures that shaped this diagnostic category. For instance, "sub-average intellectual functioning", defined as an IQ score of ≤ 84 was revised downwards to a score of ≤ 70, with a corresponding revision in wording: "significantly sub-average". This change was considered necessary in order to reduce the number of children from minority ethnic populations being labelled as intellectually disabled. Also, the diagnostic prong, "adaptive behaviour" – a person's (in)ability to function in the social environment – was, for many years, largely overlooked. It only came to hold its current prominence once the conceptual thinking behind it, and the tests necessary to measure it, gained wider acceptance amongst clinicians. Nonetheless, the most striking shift in the AAIDD's re-conceptualisation of intellectual disability has been the decision to abandon the idea that intellectual disability is a disorder – a mental or physical condition - and to see it as a disability. Embracing the CRPD's definition of disability, as an interaction between a person with impairments and their environment, the AAIDD no longer emphasises a person's deficits, but the support a person requires in order to reach their highest level of functioning. Moreover, the AAIDD explicitly calls for the government of the United States of America to adopt the CRPD. Although, somewhat inconsistently, the AAIDD asserts – contrary to Article 12 - that there may be occasions where it is necessary to restrict a person's legal autonomy (American Association on Intellectual and Developmental Disabilites, 2016). In contrast the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), published by the American Psychiatric Association, and the *International Statistical Classification of Diseases and Related Health Problems* (ICD-11 beta, is available for consultation purposes) published by the World Health Organisation, continue to identify intellectual disability as a disorder. While these two diagnostic manuals use slightly different terminology (intellectual disability as opposed to intellectual developmental disorder) their diagnostic criteria - by agreement - are the same. Indeed, the AAIDD uses essentially the same criteria, what differentiates them is solely the distinction between *disability* and *disorder*. To the extent that this difference is meaningful, it resides in the use of disability as a construct that focuses on support a person needs in order to fulfil their potential; while the construct disorder is used when determining whether a person's functional impairments are of a severity that they should receive state funded services (Carulla et al., 2011).

It is the case however, that intellectual disability, whether a disability or disorder, is based entirely upon symptoms. As such it is "meta-syndrome" (Harris, 2013) that both homogenises and glosses over the many known causes of intellectual disability: trauma before or after birth; chromosomal abnormalities; an infection present at birth or occurring afterwards; intrauterine exposure to toxins including any environmental pollutants; and malnutrition. There are, as a result, two distinct diagnostic systems operating at the same time. Diagnosis based upon functional criteria as found in the DSM and ICD manuals and bio-medical diagnoses, where an intellectual disability a symptom, amongst others, that define such underlying bio-medical conditions as, say, Down's Syndrome or foetal alcohol syndrome. With developments in medical genetics and neuroscience it is quite likely that these two diagnostic systems (one based upon a person's functional ability and the other routed in biology) will come into conflict or acquire their own spheres of professional relevance. As the situation stands at the moment, there is the potential for confusion. Persons with Down's syndrome, as a matter of routine, are often entitled to disability related services on account of the genetic condition, irrespective of their functional abilities. Whereas people with IQ scores marginally above 70 may be denied specialist services as they fail to meet eligibility criteria. In other words, recognising, or labelling a person as having an intellectual disability is an interplay between biological criteria as well as functional assessments, and where granting access to services comes with financial implications.

It should be apparent from the above discussion that when *disability* is defined in relation to specific purposes: challenging prejudice and environmental barriers; providing a multi-layered description of life with an impairment; challenging diagnostic authority; ensuring people receive the support that will enable them to achieve their full potential, and the identification of functional deficits for the purpose of determining eligibility for services. Similarly, conceptualisations of *intellectual disability* are embedded in practices that aim at unifying disabled people by down-playing differences between impairment types or measure deficits in intellectual and social functioning in order assess functional (dis)abilities, established eligibility for service or as mean to identifying a bio-medical condition. All of these different conceptions of disability and intellectual disability have potential utility and value. However, I suspect, that outside of rather rarefied contexts – perhaps the clinic or academy – these terms are used imprecisely, inconsistency and with little attention to the distinctions and debates outlined above. What might all this mean then, when considering the full and equal equality of persons with an intellectual disability? First, it creates scope for misunderstanding and disagreement, which rather neatly sums up the state of current debates over the full and equal equality of people with intellectual disabilities. Second, participants to these debates would do well to consider the extent to which by ally themselves oneself to a particular conception of disability they are overlooking the insights and value of other definitions. Third, social researchers might like to bracket concerns over the truth or falsity of these different models, and consider *how* parties to discussions over the Article 12 are using different conceptions of disability and intellectual disability (including the ambiguity between them) in order to advance and refute claims about the legal statues and characteristics of people identified as having an intellectual disability. And finally, it is possible to treat the presumption that with support that, all persons with an intellectual disability can make autonomous decisions, as an empirical question (see for example Jacob et al., 2005). Those advancing this claim could, consequently, be called upon to demonstrate this principle in actual practice.

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