Appendix 1

Glossary of terms

This glossary defines the key terms used in this dissertation. It draws on legislation and statutory guidance relating to the child protection system in England and Wales, primarily the Children Act (1989); Children Act (2004) and Working Together to Safeguard Children (HM Government, 2018).

Child protection

Child protection lies at one end of the spectrum of services and powers aimed at safeguarding and promoting children's welfare. It refers to activities undertaken to protect specific children who are suffering, or are likely to suffer, significant harm. In England and Wales child protection starts with enquiries under section 47, Children Act (1989).

Child protection system

This refers to the framework of procedures, laws, policies and services in England and Wales that work together to safeguard and promote children's welfare.

Child protection processes

This refers to the discrete range of activities involved in investigating and then intervening to address suspected, actual, or likely harm to a specific child, as defined under section 31, Children Act (1989).

In England and Wales "child protection processes" are understood as having three main parts: initial concerns about suspected, actual or likely significant harm to a specific child are first investigated via **child protection enquiries** under section 47 of the Children Act (1989); decisions may then made about how to best to safeguard the child and whether or not to hold a **child protection conference**; depending on the outcome of the child protection conference, support and help to reduce the identified harms to the child may then be provided via a **child protection plan.**

The term "child protection processes" is used in this dissertation to refer to children's overall experiences of all or any of these processes.

Child protection enquiries

This refers to the set of activities specified under section 47, Children Act 1989 as being required to investigate information or concern about whether a child is experiencing actual or likely significant harm.

Child protection conference

According to Working Together to Safeguard Children (HM Government, 2018), an initial child protection conference is a multi-agency meeting which “brings together family members (and the child where appropriate) with the supporters, advocates and practitioners most involved with the child and family to make decisions about the child’s future safety, health and development” (p. 46). If actual harm or likely harm to the child is substantiated, “decisions will be made regarding what actions are needed to protect the child” (p.46), co-ordinated via a multi-agency child protection plan.

The child’s developmental progress against child protection plan outcomes are subsequently reviewed at a second, review child protection conference, and a decision made about whether the child is continuing to suffer or is likely to suffer significant harm, and whether the child protection plan should continue or should be changed.

Child protection plan

According to Working Together to Safeguard Children (HM Government, 2018, p.46), a child protection plan is a multi-agency plan with clear actions and timescales, including a clear sense of how much improvement is needed, by when, so that its success in addressing actual or likely harm to the child and promoting their future safety, health and development can be judged clearly.

Child protection core group

According to Working Together to Safeguard Children (HM Government, 2018, p.49), this refers to the core group of practitioners, supporters and family members (including the child where appropriate) jointly responsible for developing and implementing the child protection plan for an individual child or young person.

Child protection core group meetings

According to Working Together to Safeguard Children (HM Government, 2018, p.49) this refers to meetings of members of the core group of professionals, family members and the child where appropriate. Their purpose is to monitor progress and outcomes of the actions agreed in the child protection plan in between child protection conferences and refine the plan as needed.

Child protection decision-making processes

This refers to children's overall experiences of professional decision-making during child protection processes. This is justified on the basis that it was extremely unusual for participants to refer to decisions made at specific meetings.

Child protection intervention

This refers to the range of services and powers delivered via child protection plans or other processes (e.g. via public law proceedings), aimed at either: enabling the child to continue to be cared for by their families where this is deemed sufficiently safe; or activities and interventions resulting in the child being placed in out-of-home care where this is considered necessary to protect them from harm.

Looked After Child

Looked after child is used to refer to study participants who were living in out-of-home care. It refers to a child accommodated by the local authority, as the result of either: an Interim or Full Care Order (under section 38 or 31, Children Act 1989) or a voluntary agreement with the child's parents or legal guardians (under section 20, Children Act 1989). Looked After Children in this study were placed either with foster carers or in residential children's homes.

Looked After Children's review meeting

This refers to meetings that must be held at regular intervals under Children Act (1989) guidance and regulations: Volume 2: care planning, placement and review (Department for Education, 2015). The purpose of these meetings is to: ensure that adequate plans are in place to safeguard and promote the welfare of children living in out-of-home care; and to make recommendations, as necessary, for changes to those plans.

Child in need

Child in need refers to young people in this study who were receiving support and services under section 17 (10) (b) or (c), Children Act 1989. Under this section a child is defined as being in need if: his/her health or development is likely to be significantly impaired, or further impaired, without the provision for him/her of such services; or he/she is disabled.

Child in need plan

Child in need plans detail the actions and services required to promote children’s welfare and development. Unlike child protection plans children and families can choose whether or not to accept the support and services on offer. Child in need plans are sometimes used as a way of continuing to provide support when the harm to the child has reduced so that a child protection plan is no longer considered to be required.

Appendix 2

Table of key empirical studies

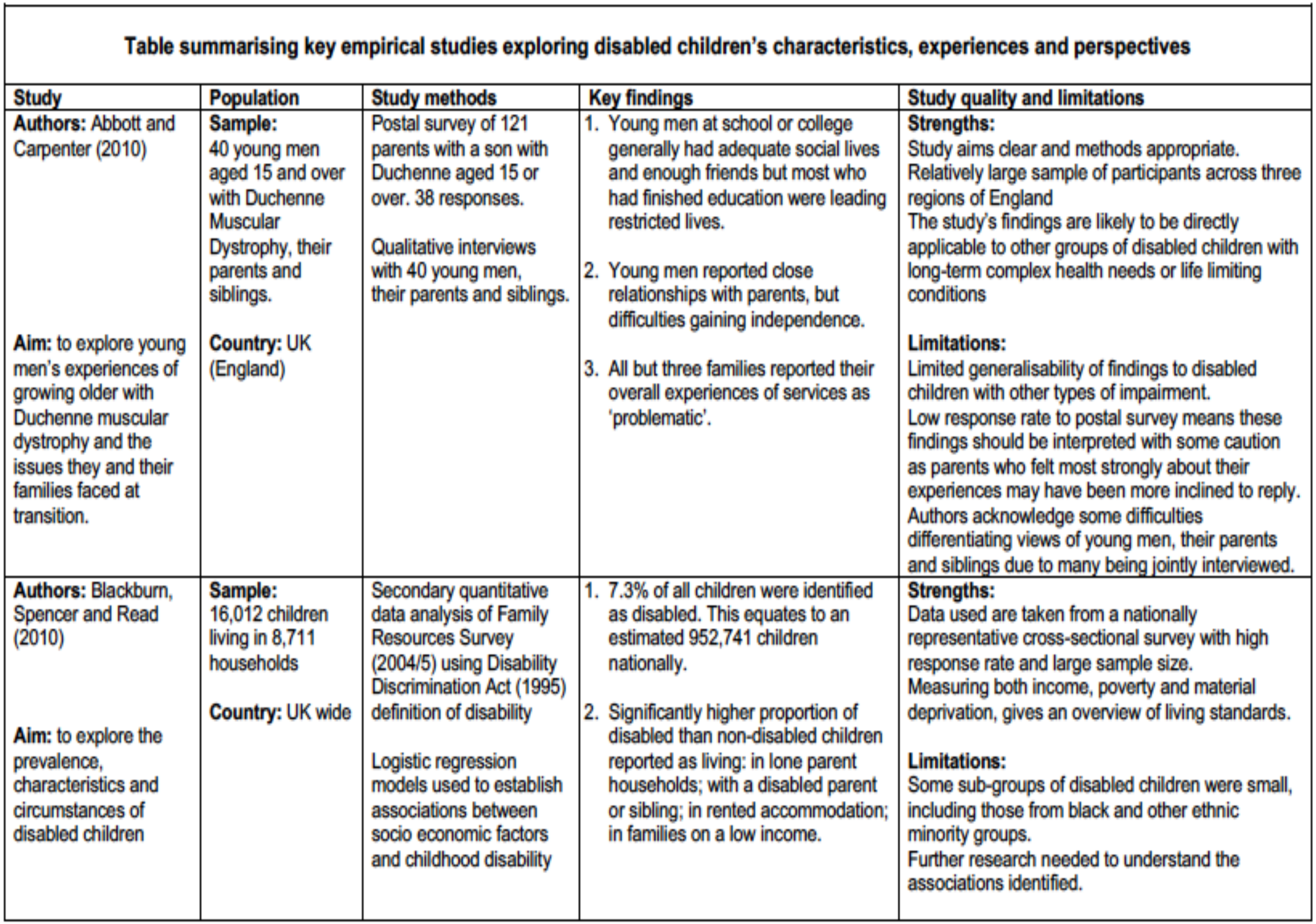


Table summarising key empirical studies exploring disabled children's characteristics, experiences and perspectives

Study	Population	Study methods	Key findings	Study quality and limitations
Authors: Abbott and Carpenter (2010) **Aim:** to explore young men's experiences of growing older with Duchenne muscular dystrophy and the issues they and their families faced at transition.	**Sample:** 40 young men aged 15 and over with Duchenne Muscular Dystrophy, their parents and siblings. **Country:** UK (England)	Postal survey of 121 parents with a son with Duchenne aged 15 or over. 38 responses. Qualitative interviews with 40 young men, their parents and siblings.	1. Young men at school or college generally had adequate social lives and enough friends but most who had finished education were leading restricted lives. 2. Young men reported close relationships with parents, but difficulties gaining independence. 3. All but three families reported their overall experiences of services as 'problematic'.	**Strengths:** Study aims clear and methods appropriate. Relatively large sample of participants across three regions of England The study's findings are likely to be directly applicable to other groups of disabled children with long-term complex health needs or life limiting conditions **Limitations:** Limited generalisability of findings to disabled children with other types of impairment. Low response rate to postal survey means these findings should be interpreted with some caution as parents who felt most strongly about their experiences may have been more inclined to reply. Authors acknowledge some difficulties differentiating views of young men, their parents and siblings due to many being jointly interviewed.
Authors: Blackburn, Spencer and Read (2010) **Aim:** to explore the prevalence, characteristics and circumstances of disabled children	**Sample:** 16,012 children living in 8,711 households **Country:** UK wide	Secondary quantitative data analysis of Family Resources Survey (2004/5) using Disability Discrimination Act (1995) definition of disability Logistic regression models used to establish associations between socio economic factors and childhood disability	1. 7.3% of all children were identified as disabled. This equates to an estimated 952,741 children nationally. 2. Significantly higher proportion of disabled than non-disabled children reported as living: in lone parent households; with a disabled parent or sibling; in rented accommodation; in families on a low income.	**Strengths:** Data used are taken from a nationally representative cross-sectional survey with high response rate and large sample size. Measuring both income, poverty and material deprivation, gives an overview of living standards. **Limitations:** Some sub-groups of disabled children were small, including those from black and other ethnic minority groups. Further research needed to understand the associations identified.

Authors: Connors and Stalker (2003) **Aim:** to explore the views and experiences of disabled children and their siblings	**Sample:** 26 disabled young people aged 7-15, 24 siblings and 38 parents **Country:** UK (Scotland)	Qualitative interviews using participatory methods with disabled children and their siblings Semi-structured qualitative interviews with parents	1. Despite participants often describing being made to feel different because of their impairments few talked about themselves as disabled. 2. Disabled children's interests and pre-occupations were same as non-disabled peers. 3. Disabled young people spoke very positively about relationships with family friends and siblings. Sibling relationships were viewed as reciprocal.	**Strengths:** One of the first studies to include interviews with disabled children with a range of impairments and the views of siblings as well as parents. Use of participatory research methods enabled younger children to take part in research **Limitations:** Most participants were recruited via voluntary organisations which may affect the generalisability of the findings to families with disabled children who do not access these services. Study participants were living in Scotland, meaning that findings relating to experiences of services and professionals may be less applicable to disabled children in other parts of the UK and elsewhere.
Authors: Dickenson *et al* (2007); Colver *et al* (2015) **Aim:** to explore self-reported quality of life among children with cerebral palsy	**Sample:** SPARCLE 1 (childhood): 500 children with cerebral palsy (8-12 yrs.) SPARCLE 2 (adolescence): 431 children with cerebral palsy (13-17 years) (355 took part in both) **Countries:** UK, Italy, Germany, Denmark, Sweden, France	KIDSCREEN, a psychometric questionnaire was used to measure self-reported quality of life (QoL) across 10 domains longitudinally during childhood and adolescents among a sample of children with cerebral palsy. Multi-variate regression was used to relate quality of life to impairment and to compare QoL data from the general population.	1. SPARCLE 1: Most children with cerebral palsy's self-reported QoL was similar to children in the general population in all domains except schooling. 2. SPARCLE 2: Adolescents with cerebral palsy had significantly lower QoL to the general population in only one domain, social support & peers. 3. Childhood QoL was a strong predictor of QoL in adolescence. Pain in childhood & adolescence was strongly associated with lower QoL life in 4 domains in childhood and 8 domains in adolescence.	**Strengths:** A strength of the study is its longitudinal design and that it draws directly on the views of young people rather than relying on views of parents as proxies. **Limitations:** The original sample was randomly selected, however, only those children who were able to self-report could take part, meaning results should be interpreted with caution in relation to children with cerebral palsy with limited communication. The study's findings may have limited generalisability to the quality of life experienced by children with other types of impairment

Authors: Foley *et al* (2012) **Aim:** to describe the meaning of well-being for children and youth with disabilities from their perspective.	**Sample:** 20 children with a range of disabilities **Country:** Australia	5 focus groups and one interview using qualitative methods, were used to encourage young people to share their experiences and perceptions of well-being Results were analysed using constant comparison methods (Charmaz, 2006)	1. Young people emphasised having good friends and family experiencing reciprocal respect in relationships, good coping strategies, feeling valued and having a positive sense of self as important to well-being. 2. Findings demonstrate the importance children and young people with disabilities place on participation and the need to 'feel belonged'.	**Strengths:** Methods and sample used highlight that children and young people can provide valuable input to research, regardless of impairment. A number of topics raised by young people themselves have not been addressed by previous well-being indicators **Limitations:** The authors acknowledge the study's small scale and sample size means further research is required to investigate the indicators disabled children consider important for their well-being. Study participants lived in Australia and contextual differences may affect the generalisability of the study's findings to other countries.
Authors: Franklin, Raws and Smeaton (2015) **Aim:** to increase understanding of how to meet the needs of children and young people with learning disabilities who experience or are at risk of child sexual exploitation (CSE)	**Sample:** 27 young people with learning disabilities aged 12-23 years who had experienced or were at risk of CSE 34 Professionals 71 local authorities/health and social care trusts **Country:** UK wide	Mixed methods study **Stage 1:** Literature review and UK policy analysis **Stage 2:** On-line survey of all local authorities policy and practice (71 of 208=34% response rate). **Stage 3:** In-depth semi-structured telephone or face-to-face interviews with 34 stakeholders in field of CSE and/or learning disability **Stage 4:** Face-to-face qualitative interviews with young people with learning disabilities who have experienced or been at risk of CSE	1. Findings indicate that children and young people with learning disabilities face additional barriers to their protection from and receiving support to address CSE. 2. These barriers: include infantilization and social isolation of people with learning disabilities; lack of access to information and education on sex and relationships; false perceptions regarding their sexual needs, wishes and desires; young people not feeling believed or listened to when they seek support with CSE. 3. Lack of formal diagnosis & accurate assessment of need contributes to the 'invisibility' of some young people with learning disability/autism at risk of CSE	**Strengths:** First study focusing on the specific needs and experiences of learning disabled young people at risk of or who have experienced CSE, including from their own perspective. Mixed methods approach combining policy analysis and views of all key stakeholders, including young people's own perspectives adds to the robustness of the study design. **Limitations:** Study focused on needs and experiences of learning disabled young people whose experiences or vulnerability to CSE has been recognised. More research is required regarding the experiences of young people whose CSE remains hidden or have never received support. More research is needed regarding the intersectionality between vulnerability to CSE related to learning disability and other identities, including gender, minority ethnic status and sexual orientation.

Authors: Franklin and Sloper (2006; 2009) **Aim:** to explore factors supporting disabled children's participation in decision-making in childrens social care	**Sample:** 21 disabled children 5-18yrs with learning or communication disabilities. 24 parents of disabled children 76 professionals 71 social services departments **Country:** UK (England wide)	Mixed methods study: **1st Stage:** 102 of 150 childrens social service departments responded to initial postal survey. Of these 71 authorities completed questionnaire regarding disabled children's participation in decision-making. **2nd Stage:** Case studies of 6 local authorities processes and outcomes of disabled children's participation. Qualitative participatory interviews undertaken with disabled children, parents and professionals.	1. 57 of 71 local authorities reported disabled children as being involved in decision-making. Evidence of disabled children participating, but is not yet sustained/embedded across areas 2. Findings from case study areas indicate tendency for local authorities to adopt a "one size fits all" approach to involving disabled children in decision-making, rather than tailoring methods to children's impairment needs. 3. Disabled children with complex needs less likely to be involved in decision-making processes and disabled children less involved in child protection decisions.	**Strengths:** Employing both quantitative and qualitative methods gave both breadth and depth to the study findings, added to the quality of the study design. Use of participatory methods allowed disabled children to demonstrate their competence to take part in research. **Limitations:** Practice in the six case study areas may have limited generalisability regarding the approach to disabled children's participation in other areas. Authors acknowledge more research is needed to understand the factors that can support and promote disabled children's effective participation
Authors: Holmbeck *et al* (2003); Holmbeck *et al* (2010) **Aim:** to investigate psycho-social adjustment and family relationships in childhood and adolescence among children with Spina Bifida	**Sample:** Matched sample of 68 children and their families with and without spina bifida between ages 8 and 15. **Country:** US	Longitudinal study of children with SB and a matched sample of typically developing children. Children and parents completed questionnaires measuring perceived psychometric and developmental functioning. Families videoed doing family interaction tasks. Growth curve models used to map & compare developmental psycho-social adjustment.	1. Differences in psychosocial adjustment for children with SB (8-9yrs) persisted in adolescence (15) indicate these young people's enduring difficulties with social and academic development and having less influence in family interactions compared with peers. 2. Young people with SB's similar psychosocial adjustment to peers on measures such as child-reported social acceptance, suggesting areas of resilience. 3. Girls with SB were at particular risk of social difficulties and negative self-perception of physical appearance in adolescence.	**Strengths:** Longitudinal study design using established measures to capture developmental trajectory of psycho-social adjustment among children with SB. Use of control group and child and parental self-report adds to robustness of study design. **Limitations:** Study findings may have limited generalisability to psychosocial adjustment of children with other impairments (e.g. learning or sensory impairments). The relatively small sample size may limit the study's capacity to detect differences between groups. Matching of the two groups would have been more robust if individual rather than group level matching had been used

Authors: Jones *et al* (2017) **Aim:** to explore deaf and disabled children and young people's experiences of help seeking & child protection systems following abuse and neglect	**Sample:** 10 deaf and/or disabled children and adults abused during childhood. 3 children 12-13yrs, 2 young adults 18-25 yrs., and 5 adults 25+	Participants took part in semi-structured "guided conversations" with an adult researcher over one or two sessions. Research materials were available in accessible formats and techniques adapted to participants' communication needs.	1. Enablers of help-seeking following abuse included the child's own defensive strategies without the intervention of adults; the capacity of adults to detect abuse and respond to disclosures and the presence of supportive contexts and relationships. 2. Participants noted a tendency for professionals to associate behaviour such as expressions of distress with impairment rather than signs of abuse, which is indicative of disabilism. 3. For deaf participants access to registered interpreters played a key role in facilitating disclosure and investigation of abuse.	**Strengths:** Study generated important findings regarding factors specifically affecting disabled children and young people's experiences of help seeking following abuse. Included perspectives of participants whose abuse had remained hidden in childhood as well as those who received support and help to stop the abuse. **Limitations:** Findings are based primarily on deaf and disabled adults' retrospective self-reported accounts of abuse experienced in childhood, which is acknowledged as a source of potential bias. A majority of participants were deaf meaning the findings should be interpreted with some caution in relation to the experiences of disabled children with other types of impairment
Author: Kelly (2005) **Aim:** to examine learning disabled children and their families perceptions of disability and experiences of family support services	**Sample:** 32 learning disabled children (aged 2-16 years), their parents (n=32) and social workers (n=16). **Country:** UK (Northern Ireland)	Participatory qualitative interviews with children using a range of communication aids to facilitate children's engagement and involvement were completed over a minimum of three visits Semi-structured interviews with parents and social workers to understand adult discourses around disability	1. Children discussed feeling different from other children, either because of disabling barriers or differences related to their impairments. 2. Children demonstrated their agency through their active participation in the research process and by giving examples of challenging circumventing the impact of negative attitudes and disabling barriers on their sense of self. 3. Parents' attitude towards child's disability appeared important in helping them negotiate disability as part of their identity.	**Strengths:** Use of participatory activities and collaborative approach important to demonstrating disabled children's competency as active participants in research. Use of perspectives of parents and social worker alongside children's perspectives facilitated reflection on theoretical understanding of disability. **Limitations:** Study participants were all living in Northern Ireland meaning that findings may be less applicable to disabled children in other parts of the UK and elsewhere due to contextual differences. Further research is required to understand longitudinal aspects of disabled children's perspectives on disability and identity during childhood and adolescence.

Author: Kelly (2013) **Aim:** Investigate learning disabled young people's transitions from child to adult life and explore their young adult life experiences.	**Sample:** 10 learning disabled young adults aged 20-29 years receiving adult learning disability services, who as children took part in Kelly's (2005) study. **Country:** UK (Northern Ireland)	Qualitative follow up study to Kelly's (2005) study (outlined above). Individual semi-structured interviews with learning disabled young adults using biographical narrative techniques to elicit identity narratives. Additional interviews with participants' main carer/parent and social workers, reading of their case files and interviews with key stakeholders in transition services.	1. The absence of meaningful friendships and social lives was a persistent theme among participants across both studies. 2. Dual transitions from school to children to further education, training or employment and from children to adult social care being simultaneously managed helped smooth participants transition to young adulthood. 3. Participants identified person-centred approaches and support for their participation as crucial to addressing the social exclusion and limited opportunities they often experience.	**Strengths:** One of few follow up studies exploring learning disabled young people's experiences and identity narratives from childhood into adulthood. Despite the study's focus on learning disabled young adults discussions with key stakeholders indicate many of the findings are salient for disabled young adults with other types of impairment. **Limitations:** Generalisability of the study's findings is limited by the small sample size, and further research is required to explore the themes identified. Study participants were living in Northern Ireland, meaning that findings relating to experiences of services and professionals may be less applicable to disabled children in other parts of the UK and elsewhere.
Authors: Kelly, Winter and Dowling (2016) **Aim:** to examine the population of disabled children in care in NI, profiling their numbers and characteristics and investigating their care experiences.	**Sample:** total sample of 487 disabled looked after (LAC) children in Northern Ireland. Full looked after, n=323, short breaks use n= 64. Case studies of 15 LAC disabled children 4-16 yrs. with a range of impairments and care experiences **Country UK** (Northern Ireland)	Multi-stage, multi-method study **Stage 1**: Review of policy context/ existing literature **Stage 2**: Quantitative survey of demographic data on all looked after disabled children in Northern Ireland. **Stage 3:** 15 qualitative case studies of looked after disabled children, involving reading case files & interviews with children and young people, carers, birth parents & social workers.	1. Disabled children over-represented among LAC children. 11.2% vs 7.3% in population. 2. High proportions of older male children with intellectual disabilities and/or mental health problems. 3. Disabled children at higher risk of placement instability & twice as likely to be in residential care. 4. Disabled children's experiences highlighted concern about bullying; lack of access to therapeutic support or advocacy; experience of being consulted/ listened to in decision-making varied.	**Strengths:** Use of both quantitative and qualitative methods and inclusion of perspectives of key stakeholders, including young people themselves added to the robustness of the study design. High response rate to request for data on LAC disabled children from local authorities (sample achieved collected equivalent to official national statistics). **Limitations:** Although the case studies successfully captured rich data on the experiences of disabled looked after children and their parents/carers, the use of professionals as gatekeepers to ensure ethical sensitivity may have prevented the inclusion of young people facing the most significant challenges as a result of living in out-of-home care.

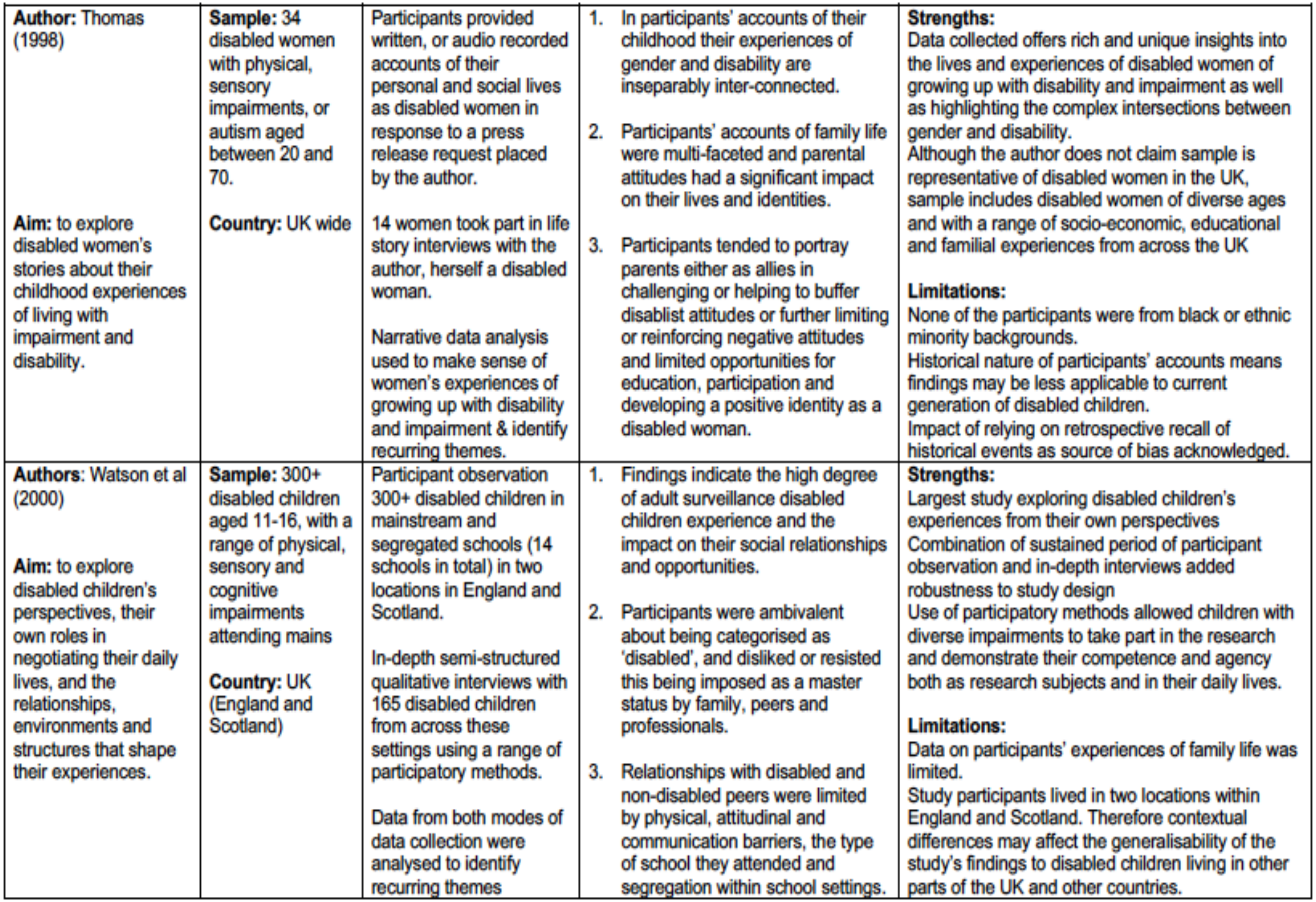
Authors: Larkins *et al* (2013) for the Office of Children's commissioner **Aim:** to explore disabled children and young people's experiences of living on a low income, using a rights-based approach	**Sample:** 78 disabled children and young people living on low incomes and 17 parents **Country:** UK (England)	Research aims, activities and materials developed by a steering group of 11 disabled young people. Qualitative semi-structured activity-based interviews 19 disabled children and young people living on low incomes and their parents. 3 focus groups with disabled children living on low incomes	1. Disabled children identified both examples of good practice and examples of their rights not being respected in all aspects of their lives. 2. Barriers participants identified to the realisation of their rights included discrimination, limits to their agency due to living on a low income and poor service provision. 3. Living on a low income was seen by participants as playing a part in barriers to the realisation of their rights in all areas of their lives except employment.	**Strengths:** Strong focus on disabled young people's own experiences of living on a low income and the use of a rights-based framework. Consistent with a rights-based approach the use of participatory activities and involvement of a steering group of disabled children and young people in co-producing the research aims, study design and data analysis. **Limitations:** Study participants lived in Northwest England. This means that findings may be less applicable to disabled children in other parts of the UK and elsewhere due to contextual differences. The framing of interview questions in terms of rights, while a strength of the study, may have affected participants' description of their lives.
Authors: Mitchell and Sloper (2011) **Aim:** to explore choices and decision-making processes for young people with life-limiting conditions	**Sample:** 27 young people with progressive life limiting health conditions aged 13-21, and their parents or carer. **Country:** UK (England)	Longitudinal study over a 3 yr period of young people with life limiting conditions views and experiences of choice and decision-making Non-traditional interview methods including symbol-based interviews used to facilitate participation of young people using non-verbal means of communication. Young people's parent or carer completed a short questionnaire and were present during some interviews.	1. Young people valued being informed and involved in decision-making, but often wanted adults to support them and/or take the lead in decision-making. 2. The role of formal carers friends as well as parents, most often "Mum" in decision-making was highlighted as important to young people, but other professionals, including social workers were rarely mentioned. 3. Young people wanted increased opportunities for making choices and greater autonomy in decision-making as they moved towards young adulthood.	**Strengths:** Longitudinal study design helped facilitate flexible approach to designing and tailoring research tools to participants' communication/learning needs. Longitudinal design also allowed researchers to capture how young people's preferences in making choices and decisions change as they move towards adulthood. **Limitations:** Study based on findings reported by young people with very specific impairments. The authors acknowledge the number of participants was small limiting the generalisability of findings to other groups of disabled children, even those with learning and/or communication impairments. The involvement of carers and other adults in interviews, whilst facilitating the inclusion of young people who otherwise might not have taken part, must be acknowledged as a source of potential bias.

Authors: McNeilly *et al* (2015) Aim: to explore participation of disabled children, their understanding of what participation means to them and their views on how practice could be improved	**Sample:** 18 disabled children and young people aged 6-28 yrs. with a range of physical, cognitive, sensory & communication impairments 77 parents or carers 90 professionals **Country:** UK (Northern Ireland)	Multi-stage, multi method study: **Stage 1**: Quantitative survey of parents and professionals **Stage 2**: Qualitative semi-structured interviews with parents **Stage 3**: Qualitative interviews with disabled children and young people using creative and participatory techniques **Stage 4:** Focus group with professionals	1. Disabled children's and young people's participation in decision-making was limited and firmly grounded in a "family-based" model. 2. Disabled young people wanted more say, and became more confident expressing their views when drawn into decision-making processes by adults. 3. Choices, information and resources to facilitate and encourage disabled young people's participation were often limited and this had a significant impact on their opportunities and lived experience.	**Strengths:** Use of both quantitative and qualitative methods and inclusion of perspectives of key stakeholders, including young people themselves added to the robustness of the study design. Use of participatory methods allowed disabled children with a wide range of impairments to demonstrate their competence to take part in research. **Limitations** Study participants all lived in one area of Northern Ireland, meaning that findings may be less applicable to disabled children in other parts of the UK and elsewhere due to contextual differences.
Authors: Raghavendra *et al* (2012) **Aim:** to investigate school participation & social networks of children with physical disabilities and complex communication needs	**Sample:** Matched sample of 39 children aged 10-15 with physical disabilities (n=11) and/or complex communication needs and (n=14) or with typical development (n=14) aged **Country:** Australia	Participants in each of the three groups were observed engaging in school activities for up to 4 hours across the school day using established measures of school participation. Participants and their parents completed a questionnaire regarding their social networks. Results from the three groups were compared using statistical methods to highlight any significant differences.	1. Participants with complex communication needs engaged in fewer comparable activities than typically developing or physically disabled children. This group also communicated less and had fewer friends in their social networks than children in the other two groups. 2. Children with physical disabilities interacted with peers and friends in similar patterns to typically developing children but with lower frequency and intensity	**Strengths:** Important findings regarding the impact of communication difficulties on disabled children's access to participation in school and social networks. Robust study design using matched sample of typically developing and physically disabled children without complex communication needs. **Limitations:** Authors note more of the children with complex communication needs attended special school compared with those with physical disabilities, meaning school environment may have contributed to findings along with impairment type. Study participants lived in Australia and contextual differences may affect the generalisability of the study's findings to other countries.

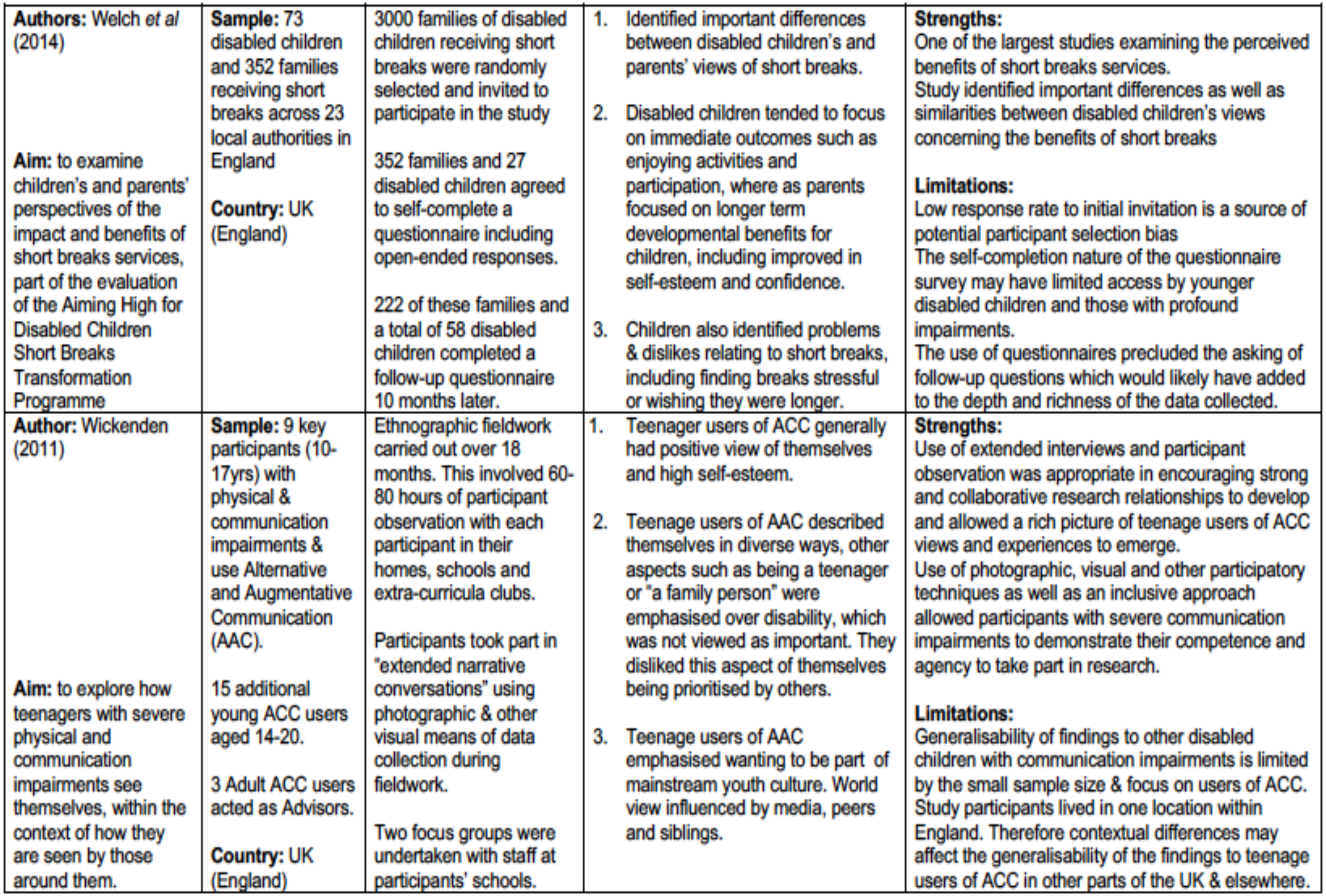
Authors: Shah and Priestley (2011) **Aim:** to investigate the relationship between changes in public policies and disabled children's family lives, opportunities, relationships & identity	**Sample:** 3 generations of physically disabled adults (50 in total) born in England in either 1940s, 1960s or 1980s. **Country:** UK (England)	Qualitative interviews using biographical narrative methods to elicit participants life histories and reflections on the impact of social policy on their experiences of growing up disabled during their childhood. Narrative analysis of data was used as a stimulus to "pose questions about parallel developments in public policies and institutions that occurred during participants' childhoods	1. Reinforced findings of other studies regarding the central importance of family bonds and resources in disabled children and young people's lives. 2. Participants life stories powerfully highlight the personal and provide consequences of segregationist social policy towards disabled children and their families, especially in the area of medicine and education 3. Participants stories demonstrated the agency and resilience of disabled children and their families in negotiating, resisting or sub-verting the impact of disablist policies & practices on their lives.	**Strengths:** Use of biographical narrative methods resulted in rich data that allowed the relationship between the personal and the political to be explored. Use of 3 cohorts of disabled children born during different historical periods allowed comparisons to be drawn regarding the impact of changing policies across the decades under consideration. **Limitations:** The authors acknowledge the diversity of factors influencing participants' individual lives and experiences and the subjective and socially constructed nature of their accounts. Relying on retrospective recall of historical events as a potential source of bias is also acknowledged. Historical nature of participants' accounts/ specific nature of their impairments means that the findings may be less applicable to the current generation of disabled children/those with other impairments
Authors: Shah, Tsitsou and Woodin (2016) **Aim:** to explore disabled women's reflections on their experiences of childhood violence, help seeking and responses to disclosure.	**Sample:** self-selected sample of 15 disabled women aged 22-56 with physical and/or sensory impairments living in various locations in England and Scotland **Country:** UK part of a larger 4 country European comparative study (Austria, Germany, Iceland)	Participants took part in qualitative semi-structured life history interviews with the author, herself a disabled woman. Narrative data analysis was used to make sense of women's experiences of violence and identify recurring themes.	1. Participants reported experiences of childhood violence across a range of contexts, but primarily perpetrated by male relatives. 2. Some participants recalled violence more specific to being disabled, for example emotional and sexual abuse exacerbated by physical dependence on abuser for care needs, and violence within segregated educational settings. 3. Dependence on perpetrator & disablist attitudes among family members and professionals acted as barriers to disclosure, or abuse being ignored or not believed.	**Strengths:** Represents important findings regarding factors affecting disabled children and young people's experiences of help seeking following abuse. Included perspectives of participants whose abuse had remained hidden in childhood as well as those who received support and help to stop the abuse. Included the perspectives of 5 participants from black and ethnic minority backgrounds. **Limitations:** Participants all lived in England and Scotland meaning participants from Wales and Northern Ireland were excluded. Findings rely on participants recovered memories of childhood violence, which have been criticised for being unreliable and clouded by subsequent experiences.

Authors: Singh and Ghai (2009) **Aim:** to capture disabled children's "lived realities" and notions of self	**Sample:** 14 children with mobility impairments aged 11-16 years **Country:** India	Semi-structured qualitative interviews with individual participants using participatory methods. Participants took part in 2 focus group discussions after individual interviews had been completed. Thematic analysis was used to code data from individual interviews and focus groups and identify recurring themes	1. Disabled children emphasised being no different from "normal children", but identified feeling disabled when unable to do certain activities. 2. Many participants described an awareness of the stigmatising gaze and reactions of others, suggesting they had internalised societal understanding of non-disabled as "normal" mode. 3. Many described their parents as overprotective due to their impairments and reported being treated differently than their siblings.	**Strengths:** Use of participatory research methods enabled children with more significant impairments to take part in research and allows children to demonstrate their understanding and agency Confirms findings of other studies regarding impact of disablist attitudes on disabled children's identity and family relationships. **Limitations:** Relatively small sample size focusing on experiences of children with mobility impairments limits the generalisability of the findings to disabled children with other impairments Study participants lived in India and contextual differences may affect the generalisability of the study's findings to other countries.
Authors: Spencer, *et al* (2005) **Aim:** to investigate the relationship between disabling conditions and child protection registration for child abuse and neglect	**Sample:** 119, 729 children consisting of all children with complete health records born in West Sussex, England, between January 1983 and December 2001 **Country: UK** (England)	Retrospective quantitative analysis of child health records for a whole population cohort of children born in West Sussex, England. Data on disabling conditions recorded as part of child health records for each child was compared with data on children in the same birth cohort with entries onto West Sussex child protection register between 1986-2003. Statistical methods of analysis were used to	1. Findings suggest children with disabling conditions are at increased risk of registration for child abuse and neglect, although the pattern varies with the specific disabling condition. 2. Associations between child protection registration and disabling conditions (which retained significance after adjustment for confounding variables, birth weight, gestational age, socio-economic status) were speech and language disorder, learning difficulties, conduct disorders and non-conduct psychological disorders.	**Strengths:** First whole population-based study reporting on relationship between disability and abuse registration. Using birth cohort data allowed relationships between disability and abuse to be compared in a whole population eliminating selection bias inherent in using selected sub-groups. Controlling for confounding variables also adds to the reliability of the findings, and is an approach used in very few previous similar studies. Using health records including disability diagnosis reduced bias associated with imprecise definitions of disability. **Limitations:** Lack of adequate data regarding date of onset of disabling conditions precluded ability to distinguish between pre-abuse and post-abuse disability.

		establish associations between disabling conditions and child protection registration overall and for each of the four possible categories, namely physical, emotional or sexual abuse or neglect.	3. Autism and sensory impairments were not associated with child protection registration. 4. Authors suggest associations between learning difficulties and conduct disorders and child protection registration is likely partly due to a shared aetiological pathway between these conditions and child abuse and neglect.	Changes to categorisation of disability (e.g. increased diagnosis of autism) and child protection registration during the period of study (19 years) is acknowledged as a potential source of mis-classification/bias
Authors: Sullivan and Knutson (2000) **Aim:** to assess prevalence of abuse and neglect as a function of disability among a population of children with and without disabilities	**Sample:** All 50,278 children aged 0-21 enrolled in school in Omaha, Nebraska in1994/ 95 school year. **Country:** US (Nebraska)	School enrolment data was electronically merged with data from Nebraska Social Services Central Registry; Nebraska Foster Care Review Board and archived data from Omaha/Douglas County to identify numbers of children exposed to maltreatment. School based disability criteria (i.e. educationally mandated disabilities) were used to distinguish between children with and without disabilities. Statistical analysis was used to identify associations between incidence and category of maltreatment and impairment type.	1. Maltreatment rates for disabled children were found to be between 3-4 times higher than those without disabilities. 2. Disabled children were significantly more likely to experience multiple forms and episodes of maltreatment. 3. Disabled children's risk of maltreatment varied with impairment type. Those at highest relative risk compared with non-disabled children were those with conduct disorders (7-fold increase) and communication disabilities (5-fold increase). 4. Disabled boys were significantly over-represented (60.4%) among maltreated disabled children.	**Strengths:** First study conducted using an entire school-based population drawn from the same geographical region thereby avoiding any subject selection bias. Using school-based disability criteria assured full inclusion of disabilities and eliminated bias due to imprecise definitions of disability. **Limitations:** Study findings, while significant, are unable to shed light on factors responsible for the associations between maltreatment and disabling conditions identified. Authors suggest further research is needed to consider the role of disabilities as a either a risk factor or an outcome of maltreatment. Study participants were all living in one US state meaning that findings may be less applicable to disabled children in other parts of the US and in other countries due to contextual differences.



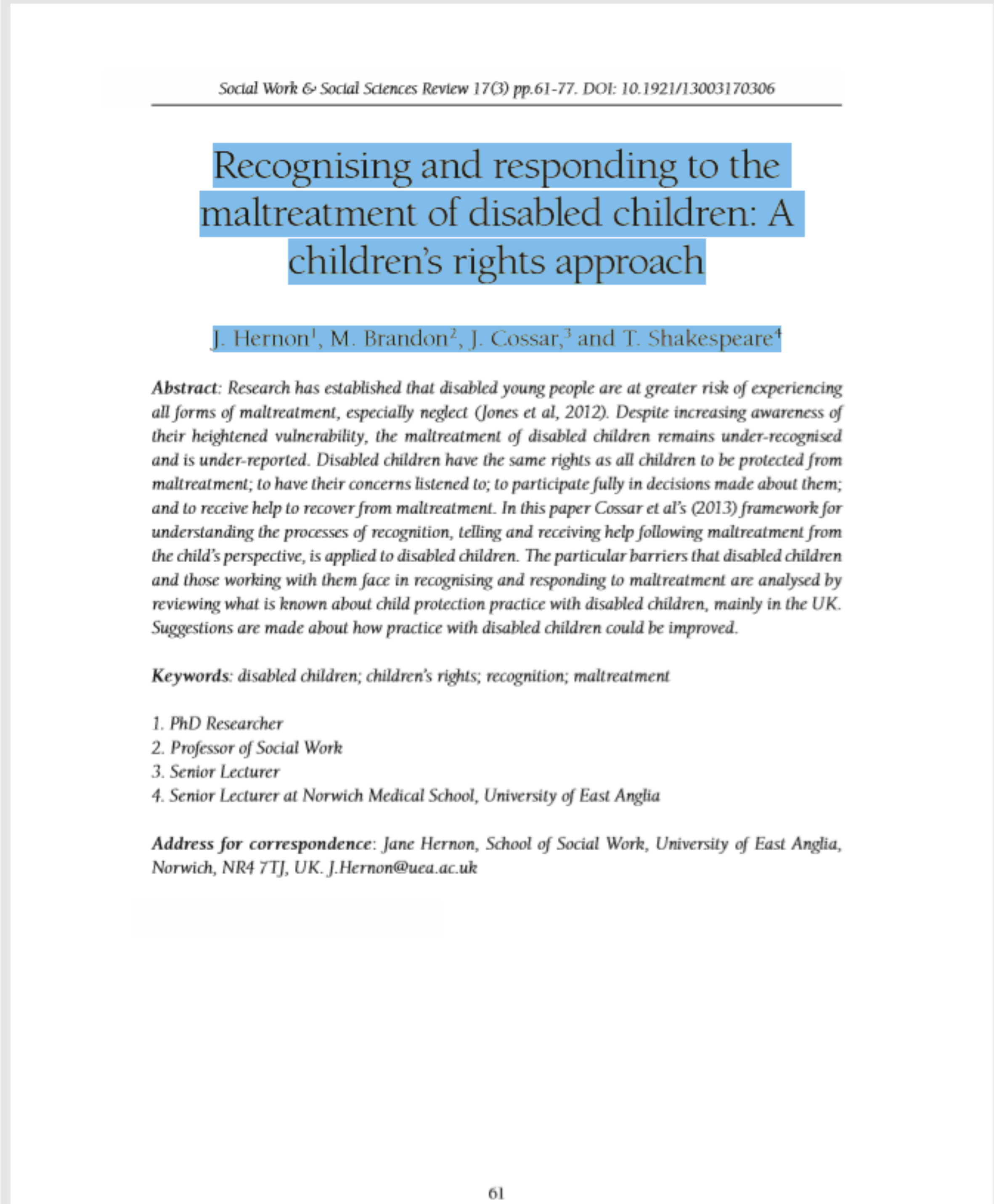
Author: Thomas (1998) **Aim:** to explore disabled women's stories about their childhood experiences of living with impairment and disability.	**Sample:** 34 disabled women with physical, sensory impairments, or autism aged between 20 and 70. **Country:** UK wide	Participants provided written, or audio recorded accounts of their personal and social lives as disabled women in response to a press release request placed by the author. 14 women took part in life story interviews with the author, herself a disabled woman. Narrative data analysis used to make sense of women's experiences of growing up with disability and impairment & identify recurring themes.	1. In participants' accounts of their childhood their experiences of gender and disability are inseparably inter-connected. 2. Participants' accounts of family life were multi-faceted and parental attitudes had a significant impact on their lives and identities. 3. Participants tended to portray parents either as allies in challenging or helping to buffer disablist attitudes or further limiting or reinforcing negative attitudes and limited opportunities for education, participation and developing a positive identity as a disabled woman.	**Strengths:** Data collected offers rich and unique insights into the lives and experiences of disabled women of growing up with disability and impairment as well as highlighting the complex intersections between gender and disability. Although the author does not claim sample is representative of disabled women in the UK, sample includes disabled women of diverse ages and with a range of socio-economic, educational and familial experiences from across the UK **Limitations:** None of the participants were from black or ethnic minority backgrounds. Historical nature of participants' accounts means findings may be less applicable to current generation of disabled children. Impact of relying on retrospective recall of historical events as source of bias acknowledged.
Authors: Watson et al (2000) **Aim:** to explore disabled children's perspectives, their own roles in negotiating their daily lives, and the relationships, environments and structures that shape their experiences.	**Sample:** 300+ disabled children aged 11-16, with a range of physical, sensory and cognitive impairments attending mains **Country:** UK (England and Scotland)	Participant observation 300+ disabled children in mainstream and segregated schools (14 schools in total) in two locations in England and Scotland. In-depth semi-structured qualitative interviews with 165 disabled children from across these settings using a range of participatory methods. Data from both modes of data collection were analysed to identify recurring themes	1. Findings indicate the high degree of adult surveillance disabled children experience and the impact on their social relationships and opportunities. 2. Participants were ambivalent about being categorised as 'disabled', and disliked or resisted this being imposed as a master status by family, peers and professionals. 3. Relationships with disabled and non-disabled peers were limited by physical, attitudinal and communication barriers, the type of school they attended and segregation within school settings.	**Strengths:** Largest study exploring disabled children's experiences from their own perspectives Combination of sustained period of participant observation and in-depth interviews added robustness to study design Use of participatory methods allowed children with diverse impairments to take part in the research and demonstrate their competence and agency both as research subjects and in their daily lives. **Limitations:** Data on participants' experiences of family life was limited. Study participants lived in two locations within England and Scotland. Therefore contextual differences may affect the generalisability of the study's findings to disabled children living in other parts of the UK and other countries.



Authors: Welch *et al* (2014) **Aim:** to examine children's and parents' perspectives of the impact and benefits of short breaks services, part of the evaluation of the Aiming High for Disabled Children Short Breaks Transformation Programme	**Sample:** 73 disabled children and 352 families receiving short breaks across 23 local authorities in England **Country:** UK (England)	3000 families of disabled children receiving short breaks were randomly selected and invited to participate in the study 352 families and 27 disabled children agreed to self-complete a questionnaire including open-ended responses. 222 of these families and a total of 58 disabled children completed a follow-up questionnaire 10 months later.	1. Identified important differences between disabled children's and parents' views of short breaks. 2. Disabled children tended to focus on immediate outcomes such as enjoying activities and participation, where as parents focused on longer term developmental benefits for children, including improved in self-esteem and confidence. 3. Children also identified problems & dislikes relating to short breaks, including finding breaks stressful or wishing they were longer.	**Strengths:** One of the largest studies examining the perceived benefits of short breaks services. Study identified important differences as well as similarities between disabled children's views concerning the benefits of short breaks **Limitations:** Low response rate to initial invitation is a source of potential participant selection bias The self-completion nature of the questionnaire survey may have limited access by younger disabled children and those with profound impairments. The use of questionnaires precluded the asking of follow-up questions which would likely have added to the depth and richness of the data collected.
Author: Wickenden (2011) **Aim:** to explore how teenagers with severe physical and communication impairments see themselves, within the context of how they are seen by those around them.	**Sample:** 9 key participants (10-17yrs) with physical & communication impairments & use Alternative and Augmentative Communication (AAC). 15 additional young ACC users aged 14-20. 3 Adult ACC users acted as Advisors. **Country:** UK (England)	Ethnographic fieldwork carried out over 18 months. This involved 60-80 hours of participant observation with each participant in their homes, schools and extra-curricula clubs. Participants took part in "extended narrative conversations" using photographic & other visual means of data collection during fieldwork. Two focus groups were undertaken with staff at participants' schools.	1. Teenager users of ACC generally had positive view of themselves and high self-esteem. 2. Teenage users of AAC described themselves in diverse ways, other aspects such as being a teenager or "a family person" were emphasised over disability, which was not viewed as important. They disliked this aspect of themselves being prioritised by others. 3. Teenage users of AAC emphasised wanting to be part of mainstream youth culture. World view influenced by media, peers and siblings.	**Strengths:** Use of extended interviews and participant observation was appropriate in encouraging strong and collaborative research relationships to develop and allowed a rich picture of teenage users of ACC views and experiences to emerge. Use of photographic, visual and other participatory techniques as well as an inclusive approach allowed participants with severe communication impairments to demonstrate their competence and agency to take part in research. **Limitations:** Generalisability of findings to other disabled children with communication impairments is limited by the small sample size & focus on users of ACC. Study participants lived in one location within England. Therefore contextual differences may affect the generalisability of the findings to teenage users of ACC in other parts of the UK & elsewhere.

Appendix 3

Hernon *et al* (2015).



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Recognising and responding to the maltreatment of disabled children: A children's rights approach

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Abstract: *Research has established that disabled young people are at greater risk of experiencing all forms of maltreatment, especially neglect (Jones et al, 2012). Despite increasing awareness of their heightened vulnerability, the maltreatment of disabled children remains under-recognised and is under-reported. Disabled children have the same rights as all children to be protected from maltreatment; to have their concerns listened to; to participate fully in decisions made about them; and to receive help to recover from maltreatment. In this paper Cossar et al's (2013) framework for understanding the processes of recognition, telling and receiving help following maltreatment from the child's perspective, is applied to disabled children. The particular barriers that disabled children and those working with them face in recognising and responding to maltreatment are analysed by reviewing what is known about child protection practice with disabled children, mainly in the UK. Suggestions are made about how practice with disabled children could be improved.*

Keywords: *disabled children; children's rights; recognition; maltreatment*

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Introduction

Child maltreatment and its associated consequences are a major global public health concern, which has been the subject of international attention in recent decades. This has been prompted, not least through the introduction of the UN Convention on the Rights of the Child (UNCRC, 1989). This sets out states' responsibilities to respect and ensure children's rights to protection (Article 19); to express their views and to have these views taken seriously (Article 12); to be provided with support, including to aid recovery from abuse (Article 36). These core rights are seen as crucially interconnected within a children's rights approach to maltreatment (UN Committee on the Rights of the Child, 2003), and have guided much recent child welfare policy development, especially in high-income countries (Reading et al, 2009).

All children, including disabled children, have the same rights (Article 2). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) reinforces states' responsibilities to provide for disabled children's additional needs in sustaining their equal rights, including the right to express their views (Article 7) and that of protection (Article 16). However the overlap between disability and maltreatment has generally received much less attention Mikton, Maguire, & Shakespeare, 2014). This paper discusses the evidence linking disability with maltreatment, before reviewing what is known about recognising and responding to maltreatment involving disabled children. It then considers how practice might be improved, using Cossar et al's (2013) framework for understanding recognition, telling and help, based on children's perspectives about maltreatment.

Disabled children and maltreatment

Disabled children have long been considered at greater risk of violence and maltreatment (Kelly, 1992; Sobsey, 1994; Westcott and Jones, 1999). A substantial body of evidence now exists to support this assertion. While estimates vary, a recent meta-analysis confirmed Sullivan and Knutson's (2000) earlier work, finding violence and maltreatment to be 3 to 4 times more common among disabled children, with emotional abuse and neglect most prevalent (Jones et al, 2012). Several studies indicate that disabled children's risk of maltreatment varies according to impairment type, with having a mental or intellectual disability, communication impairment or behavioural difficulty being more strongly associated with maltreatment (Sullivan and Knutson, 2000; Spencer et al, 2005; Jones et al, 2012).

Despite persistent evidence linking disability with maltreatment, the underlying causes for this association remain poorly understood. Robust, well-designed studies on this topic remain scarce, with very few population-based studies, and only a handful of studies adequately controlling for possible confounding factors, such as birth-weight and socio-economic status (Jones et al, 2012). Wide variation in how disability and maltreatment are defined also makes comparison across different studies difficult, further contributing to a lack of clarity regarding prevalence rates (Jones et al, 2012). Current studies also shed little light on the important question of the extent to which disability can be a consequence of, rather than a risk factor for maltreatment (Jones et al, 2012), and much literature gives scant consideration to theoretical perspectives (Leeb et al, 2012).

Nevertheless, a number of possible explanations for disabled children's increased risk of maltreatment have been proposed. Early theories suggested disabled children's additional difficulties and support needs potentially triggered maltreatment due to increased parental stress (Ammerman, 1991). Empirical evidence has provided little support for this explanation, however, since severity of disability does not necessary correlate with increased parental stress or risk of maltreatment (Benedict et al, 1992; Verdugo et al 1995). Conversely, Spencer et al 2005, suggest the higher numbers of children with learning difficulties or behavioural problems they found who were the subject of a child protection plan, was due partly to these conditions more often occurring as a direct consequence of neglectful parenting.

More recent accounts, drawing on transactional-ecological understandings of child development and maltreatment (Cicchetti et al, 2000), explain the association between disability and maltreatment as arising from complex interactions between vulnerability factors in the child, their carers and the wider environment. At an individual level the quality of the attachment relationship between a child and his or her carers is seen as promoting or impeding the potential for both development and maltreatment. Howe (2006) argues it is this factor, rather than the presence of disability *per se*, that accounts for increased maltreatment rates among disabled children. This assertion is supported by a meta-analysis finding lower levels of secure attachments and slightly more disorganised attachments among disabled children (van IJzendoorn et al, 1992).

Transactional-ecological perspectives may also help explain evidence of interrelationships between disability, maltreatment and other forms of disadvantage. For example, numerous studies have identified increased incidence of both disability and maltreatment among children from lower socio-economic backgrounds (e.g. Blackburn et al, 2010; Sidebotham et al, 2002). Carers of disabled children are also more likely to experience social isolation and financial problems, due to higher costs and reduced employment opportunities (Leeb et al, 2012), factors that have been shown to cumulatively affect maltreatment risk (Stith et al, 2009; MacKenzie et al, 2011).

In addition, interactions between disability and other socio-demographic variables may help account for the different maltreatment patterns noted among disabled children (Stalker and McArthur, 2012). For example, most evidence put disabled boys at even higher risk of maltreatment than non-disabled boys (Kvam, 2000), in one study making up 70.3% of maltreated disabled children (Sullivan and Knutson, 2000). Herschkowitz et al (2007) also found disabled boys were significantly more likely than disabled girls to experience physical abuse, but less likely to be sexually abused. However, Briggs (2006) found disabled boys were equally likely to experience sexual abuse, but less likely to report it.

Evidence regarding how other factors may influence disabled children's risk of maltreatment is less clear. For example, while Sullivan and Knutson (2000) found maltreatment of disabled children began at earlier ages, Herschkowitz et al (2007) found no such differences. Similarly, while cultural and religious attitudes towards disability have been shown to affect disabled children's experiences and life chances (Danseco, 1997; United Nations, 2006), most research indicates no differences in maltreatment and disability rates between different races (Gourdine, 2013). However, one study found maltreatment rates were significantly higher among white children than Hispanic children and those from other ethnic minorities (Jaudes and Mackey-Bilaver, 2008).

Negative prevailing social attitudes and discrimination towards disabled people, highlighted by social models of disability (Westcott and Jones, 1999), may help explain other evidence suggesting maltreatment involving disabled children tends to be more severe (Sullivan and Knuston, 2000; Kvam, 2004), is often more violent (Akbas et al, 2009), and is more likely to involve multiple forms and recurrent episodes of abuse than that involving non-disabled children (Sullivan and Knutson, 2000). However, while it seems reasonable to conclude from the evidence reviewed above, that disability represents an important risk factor for maltreatment, this association and its underlying causes are complex and variable (Stalker and McArthur, 2012; Leeb et al, 2012).

Recognising and Responding to the maltreatment of disabled children

Given that disabled children are at greater risk of maltreatment, recognising and responding to maltreatment involving disabled children should be a priority. Yet recent reviews identified several areas of concern in relation to child protection practice with disabled children in the UK (Ofsted, 2012; Taylor et al, 2014). Stalker et al's (2010) policy review concluded that disabled children were 'almost invisible' within mainstream child protection policies in the 4 UK countries, and the Munro Review of Child Protection in England and Wales (HM, 2011) made no reference to disabled children's increased risk of maltreatment, illustrating an underlying trend for childhood disability to be regarded as a separate policy issue (Stalker, 2012).

The remainder of this paper applies Cossar et al's (2013) framework for understanding recognition, telling and help from children's perspectives about maltreatment, to what is known about recognising and responding to maltreatment involving disabled children. Suggestions are made about how practice with disabled children might be improved and their rights upheld. It is important to acknowledge, however, that disabled children's heterogeneity (Watson, 2012) means that their experiences of maltreatment and seeking help are likely to be as complex and varied as those described by non-disabled children. Research regarding disabled children's own perspectives about maltreatment and child protection is also lacking, and represents an important direction for future research (Stalker and McArthur, 2012).

Approach to literature search

A narrative rather than systematic approach was taken to identifying relevant literature, and a range of search strategies was used. This reflects the need to include grey (unpublished) literature given its relevance to practice, and the dearth of empirical research on this topic (Stalker and McArthur, 2012). The findings of practice inspections (Ofsted, 2012), policy reviews (NSPCC 2003; Stalker et al 2010) and reports of empirical studies (Brandon et al, 2011; Taylor et al 2014) are therefore discussed alongside research published in peer-reviewed academic journals.

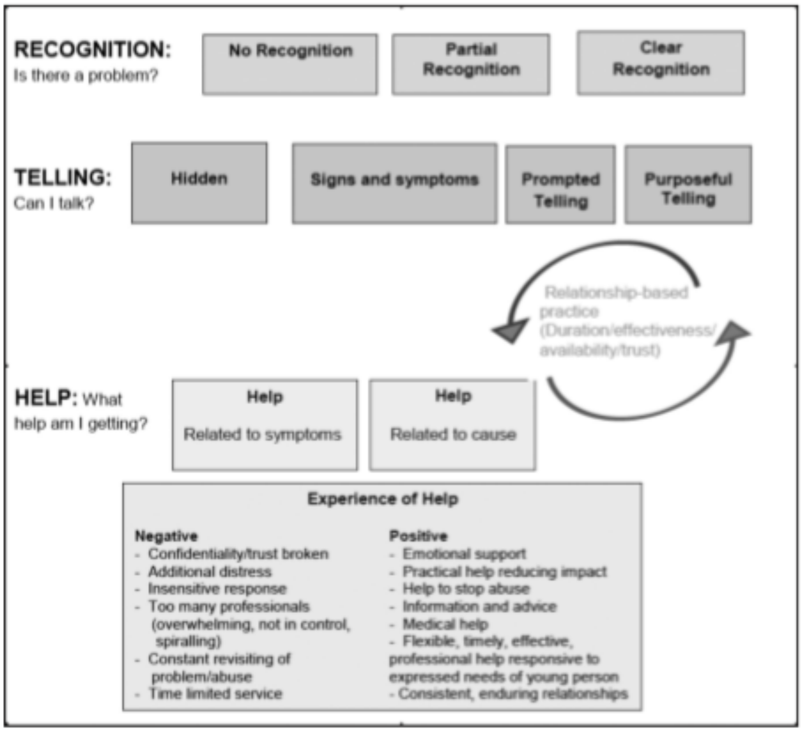
Journal articles were retrieved by entering key search terms, (disab*, child welfare, protect*, maltreatment, abuse) into Metalib, (including MEDLINE and Applied Social Sciences Index (ASSIA) databases). Unpublished literature was retrieved by entering these search terms into Google and Google Scholar. Further literature was obtained through searching the bibliographies of relevant articles and reports, and via key informants in research and practice. While the review focuses on the UK, the barriers disabled children and practitioners experience recognising, telling and receiving help with maltreatment seem likely to be similar in other high income countries (Lightfoot and La Liberte, 2013; Kvam, 2004), despite variations across child welfare systems (Thoburn, 2013). Therefore international literature is referred to where relevant.

The majority of the empirical studies examined employ qualitative methods, with findings based on interviews and focus groups with practitioners and managers working with disabled children in child protection. The quality of evidence varies, for example studies often relied only on recall and self-report. Qualitative studies lack generalisability due to their small sample sizes. As already stated, disabled children's perspectives on maltreatment and child protection remain largely unknown (Stalker and McArthur, 2012). Quantitative surveys, seeking to understand disabled children's presence within child welfare processes, are limited by wide variation in how disability and maltreatment are defined (Lightfoot and La Liberte, 2011) and by poor recording practices (Cooke and Standen, 2002). Despite these limitations, the studies reviewed highlight a number of consistent themes concerning child protection practice with disabled children (Osborne, 2013).

Recognising and responding to maltreatment: The child's perspective

From a children's rights perspective, understanding what children say helps them is essential for improving their access to support and protection, and for remaining focused on outcomes for the child (HM, 2011). Cossar et al's (2013) research explored how the processes of recognising and telling about maltreatment and receiving help are experienced from the child's perspective. Their study consisted of a structured literature review, content analysis of an online peer support website, in-depth qualitative interviews with thirty young people aged 11-20 at risk of maltreatment, and six focus groups with young people, parents, and practitioners. Findings were used to develop a conceptual framework to help practitioners understand both the barriers children face in recognising maltreatment and talking about it, and also how the responses children receive can promote or hinder their capacity to tell someone about maltreatment and access help.

Figure 1
Framework for Recognition, Telling and Help, Cossar et al (2013)



Cossar et al's (2013) framework seems particularly relevant for disabled children given they are at greater risk of maltreatment (Jones et al, 2012) and that maltreatment involving disabled children is under-recognised and under-reported (Cooke and Standen, 2002; Ofsted, 2012). Contributing to this under reporting is evidence that disabled children themselves are less likely to report maltreatment (Herschkowitz et al, 2007). Practitioners may also tend to disregard disabled children's accounts (Kvam, 2004) or wrongly attribute signs of maltreatment to children's impairments (Brandon et al, 2011), contributing to maltreatment involving disabled children remaining undetected.

Recognition

Cossar et al's (2013) research identified recognition of maltreatment along a spectrum, from 'no recognition' to 'clear recognition', with many children describing their understanding as beginning with an emotional awareness that things were not right ('partial recognition'). Recognition was often gradual, and it was not the case that children first recognised maltreatment, then told about it, and then received help. Sometimes children recognised maltreatment only after receiving help. Barriers to recognising maltreatment included children feeling they deserved it; difficulty acknowledging adults, particularly parents as abusive (especially where relationships were sometimes good); confusion about boundaries between discipline and physical abuse and differences between appropriate and inappropriate touching in relation to sexual abuse (Cossar et al, 2013). Children found recognising emotional abuse or neglect especially difficult (Cossar et al, 2013).

Research with disabled children suggests that these barriers may be especially challenging for some disabled children. For example, many disabled young people in Connors and Stalker's (2007) research had experienced others making them feel different or of lesser value because of their impairments, and over half had experienced bullying. In the context of maltreatment, the negative messages some disabled children may have internalised about their impairments could make it more likely that they would blame themselves. Disabled children's access to social networks and friendships may be restricted as a result of attending special schools considerable distances from their homes, mobility difficulties or parents' protectiveness towards learning disabled children (Watson et a, 1999; Kelly, 2005). Reduced opportunities to visit or spend time with friends, limits disabled children's possibilities for comparing their situations and families with those of others, which Cossar et al (2013) identified as central to children's recognition of maltreatment.

Differentiating between appropriate and inappropriate touch, can be more challenging for disabled children who have always relied on others for intimate care; who may have become accustomed to allowing others unrestricted access to their bodies; or may be physically less able to stop abuse from happening (Murray

and Osborne, 2009). Children's impairments can themselves also act as a barrier to recognising maltreatment. For example, cognitive impairments or autism can affect children's emotional development and ability to understand appropriate boundaries and to recognise others' behaviour as abusive. Deaf children and children with communication difficulties may also lack access to information about, and consequently understanding of, maltreatment (Murray and Osborne, 2009). All these factors contribute to disabled children being less able to recognise maltreatment, and potentially to them being targeted by perpetrators (Westcott and Jones, 1999).

Telling

Cossar et al (2013) identified a similar spectrum related to telling, ranging from maltreatment remaining 'hidden', being signalled by changes in children's behaviour or presentation ('signs and symptoms'), through to children's 'prompted telling' (through another person persisting in enquiring about their welfare) or 'purposeful telling' about maltreatment (the child sought someone out to tell about maltreatment). The first two categories, 'hidden' where the child may be actively denying maltreatment, or is showing 'signs and symptoms' of maltreatment, do not require that the child him or herself recognises the maltreatment. Even where children recognised what was happening was wrong they experienced many barriers to telling. These included: fear of consequences or of not being believed; struggling to find or express the right words; feeling ashamed or embarrassed; worrying about the impact on family relationships; or being threatened by their abuser (Cossar et al, 2013).

Many of the factors contributing to disabled children's difficulties recognising maltreatment may also affect their capacity to tell someone about their experiences. For example, the social isolation of some disabled children can mean they are less likely to have a trusted friend or adult to talk to about their problems. Recent research studies in Australia and Norway highlight how this is particularly true of children with complex communication impairments (Raghavendra et al, 2013), and learning difficulties (Ytterus, 2012). In addition, children with these impairments may be less likely to have access to someone with the necessary skills to explain to them about maltreatment, or lack access to appropriate vocabulary to understand and communicate about these issues (Murray and Osborne, 2009). Disclosing maltreatment can also be more risky for children who may be physically dependent on their abuser (NSPCC, 2003).

Disabled children have the same rights as all children to express their concerns, whether directly or through their behaviour, and for those concerns to be taken seriously. However, practitioners' report generally feeling ill-equipped to facilitate disclosures of maltreatment by disabled children, particularly children with communication and learning impairments (Cooke and Standen, 2002; Taylor et al, 2014). This factor may contribute to practitioners tending to disbelieve disabled children's accounts. For example Kvam's (2004) retrospective study of 302 deaf adults in Norway, found 10% of those who reported being abused as children, were not believed. In addition, practitioners report particular difficulties interpreting changes in disabled children's behaviour that might indicate maltreatment (Orelove et al, 2000; Cooke and Standen, 2002). This may lead practitioners to mis-attribute signs of maltreatment to children's impairments. For example, an analysis of practice in a sample of serious case reviews identified instances of bruising being implausibly accepted as related to children's impairments, and of practitioners failing to adequately scrutinise alternative explanations. A tendency to 'see the disability, not the child' was also identified as contributing to maltreatment involving disabled children being missed (Brandon et al, 2011). While there are occasionally instances where maltreatment is wrongly suspected when the issue is the impairment, for example fractures in osteogenesis imperfecta (Hibbard and Desch, 2007), it is worrying that the fear of getting it wrong can deter some practitioners from acting on concerns for disabled children (Taylor et al, 2014).

Ofsted's (2012) inspection of English practice identified 'too many' cases where social workers had failed to identify child protection concerns for disabled children already receiving support via children in need services. Other evidence suggests higher child protection referral thresholds are sometimes applied to disabled children. For example practitioners in Taylor et al's (2014) study reported that 'a wee bit of neglect' was more likely to be tolerated in cases involving disabled children, because practitioners over-empathised with parents due to the additional stress of caring for a disabled child. Brandon et al's (2011) analysis of serious case reviews identified similar instances of agencies accepting a different or lower standard of care for disabled children than their non-disabled peers. Cooke and Standen's (2002) survey study also found that maltreatment involving disabled children was less likely to be recognised until the signs and symptoms were severe.

Recent inspection reports and research with practitioners found however, that a wide range of professionals identify and appropriately refer concerns for disabled children (Ofsted, 2012; Taylor et al, 2014). Taylor et al' s (2014) research also found direct disclosure by disabled children triggered the most child protection referrals in the Scottish cases they examined, leading them to conclude that the numbers of disabled children who lack the capacity to recognise and communicate about maltreatment may be overstated by practitioners. A number of research studies with disabled children have emphasised their capacity for agency (Watson et al, 1999; Connors and Stalker, 2003), including research with young people with complex communication impairments (Wickenden, 2011) and learning difficulties (Kelly, 2005). All the above examples underline the increased onus on practitioners to develop the communication skills and child protection knowledge required to understand and listen to disabled children, rather than just relying on children's capacity to report maltreatment (Brandon et al, 2011).

Helping

Practitioners' availability and reliability was considered important in determining the quality of help received by young people in Cossar et al's (2013) study. Help provided to address maltreatment symptoms, indicated by children's behaviour or distress, included mental health services or help with anger management. Such help was often provided without the maltreatment underlying these problems being recognised or addressed, for example via child protection enquiries (Cossar et al, 2013). Children who experienced child protection processes valued access to clear information and being listened to and involved in decision-making, but disliked having too many professionals involved or being interrogated as a source of evidence (Cossar et al, 2011).

Disabled children have the same rights to access these helping processes as non-disabled children. Again, evidence suggests that in practice disabled children's access to these services may not be the same. For example, Cooke and Standen (2002) found that disabled children were significantly less likely to have a child protection plan following child protection conferences than were non-disabled children (54% vs 82%). Disabled children made up only 3.8% of children receiving support via child protection plans in England and Wales in 2011 (DfE, 2011), despite approximately 7% of children being disabled (Ofsted, 2012). Poor recording practices may contribute, however, to disabled children's apparent under-representation within child protection systems (Cooke and Standen, 2002).

Disabled children's experience within child protection processes often differs from that of non-disabled children in other ways. For example, successive reviews have found that disabled children are less likely to be spoken to during child protection enquiries (Cooke and Standen, 2002; NSPCC, 2003; Ofsted, 2012). Taylor et al's (2014) research found that practitioners often struggle to adapt child protection procedures to meet disabled children's needs. Frontline practitioners often lack necessary skills for communicating with disabled children, however arrangements to involve professionals with appropriate expertise are *ad hoc*. Practitioners' difficulties engaging with disabled children can lead to an over-reliance on parents' views, meaning children's perspectives can be overlooked (Brandon et al, 2011). Other research highlights that a medical or impairment-centred approach predominates in child protection enquiries concerning disabled children. For example Cooke and Standen (2002) found disabled children were more likely to undergo medical examination and/or treatment than were non-disabled children. Manders and Stoneman (2009) study also found US child protection workers were more likely to view disabled children in case vignettes as having characteristics that had contributed to the maltreatment.

Ofsted's (2012) recent inspection report identified examples of disabled children's views being successfully included in assessments. Practitioners in Taylor et al's (2014) study similarly identified examples of child protection processes being successfully adapted to obtain disabled children's accounts. However, even in these cases, disabled children's evidence tended to be regarded as unreliable by police or prosecutors, and none of the cases examined by Taylor et al (2014) had resulted in criminal proceedings. While adequate steps had reportedly been taken to protect these children, a lack of access to criminal justice is disempowering, and may affect children's willingness to report future concerns and access help (Cossar et al, 2013).

Disabled children have an equal right to help with recovering from maltreatment, yet evidence suggests that maltreated disabled children's access to services to specifically meet these needs is unequal. Cooke and Standen's (2002) survey, for example found that disabled children were less likely to be referred for therapeutic support following substantiated maltreatment. Although Ofsted (2012) found that most disabled children with child protection plans made good progress, these plans lacked a focus on outcomes for the child, and advocacy services were rarely used to understand disabled children's own perspectives of their support needs. In addition, Taylor et al (2014) highlighted a shortage of suitably trained foster-carers as adversely affecting child protection practice with disabled children, which in one case had delayed a disabled child being removed from a risky family situation.

Discussion

In this paper Cossar et al's (2013) framework for understanding the processes of recognition, telling and accessing help following maltreatment from the child's perspective was applied to disabled children. The particular barriers that disabled children and those working with them may face in recognising and responding to maltreatment were analysed by reviewing the available evidence. Cossar et al's (2013) framework could itself be used to help address some of the issues raised, for example to train practitioners working with disabled children to remain alert to the possible meaning of changes in their behaviour, and whether or not these might indicate maltreatment.

This review identified some examples of effective child protection practice with disabled children. Understanding from these examples could be usefully applied to improve practice more widely. For example Taylor et al (2014) identified inter-agency working, and pooling of skills and knowledge between practitioners as strategies that improved practitioner confidence in their ability to recognise and communicate with disabled children about possible maltreatment. Ofsted's (2012) recent inspection found evidence of disabled children's views being ascertained by staff that knew them well, with observational techniques being used to interpret the behaviour of children with complex needs. Having reliable access to someone who knows them well and whom they can trust is also important from children's perspectives. Receiving a sensitive response from practitioners was highlighted by young people in Cossar et al's (2013) study as critical to establishing a trusting relationship where they could begin to tell about maltreatment.

Analyses of child protection referrals involving disabled children highlight teachers and other school staff as especially important in recognising maltreatment, including that disclosed directly by children themselves. School staff accounted for 36.2% of substantiated maltreatment in Orelove et al's (2000) survey, and 44% of referrals in cases examined by Taylor et al (2014). This highlights the need to ensure that all staff members working directly with disabled children have access to awareness training on disabled children's greater risk of maltreatment. Schools also have an important role to play in providing disabled children with the same access as non-disabled children via the curriculum to relationship and sex education, opportunities to discuss healthy relationships and clear information about how to recognise maltreatment and seek help (Cossar et al, 2013). Learning should be tailored to meet disabled children's communication and learning needs and a range of practice resources have been developed for this purpose (see Murray and Osborne, 2009).

Ofsted's (2012) inspection of practice in England identified many cases where emerging concerns for disabled children were identified and dealt with effectively through multi-agency support at an early stage, preventing the need for child protection involvement. Taylor et al's (2014) research also highlighted the need to review services provided to disabled children during and following child protection enquiries to ensure these are appropriate to their needs. Their suggestions include adapting child protection conferences to include disabled children and increasing the number of foster carers able to provide placements for disabled children. Highlighting factors that promote good practice also needs to be reinforced by evidence that these interventions are cost-effective, especially in financially straightened times. However, a recent systematic review identified a lack of research regarding the effectiveness of interventions to prevent and respond to maltreatment involving disabled children (Mikton et al, 2014), and this represents an important direction for future research. One suggestion was that, parenting programmes shown to be effective in preventing child maltreatment could be adapted for families with disabled children and evaluated for effectiveness (Mikton et al, 2014).

Conclusion

Disabled children have the same rights as all children to be protected from maltreatment. They also have the same rights to express themselves and to have their concerns listened to and appropriately acted upon, to participate fully in decisions made about them and to receive support for themselves to aid recovery from maltreatment. Given evidence that disabled children are at greater risk of maltreatment, efforts to recognise and respond to maltreatment concerning them should be afforded greater priority. However, evidence suggests disabled children in the UK generally have poorer access to support and help at all stages of the child protection process.

Accurately recognising maltreatment involving disabled children is admittedly often more complex and time consuming for everyone concerned. However, examples of effective practice, even with children with very complex needs, highlights practitioners' obligation to ensure they have appropriate knowledge and skills to communicate with disabled children about possible maltreatment, rather than relying on disabled children themselves to report it. Practitioners also need to remain alert to changes in disabled children's behaviour that may indicate possible maltreatment. A key recent finding, however, is that disabled children often have a greater capacity to recognise and report maltreatment than is recognised by practitioners (Taylor et al 2014). This underlines the importance of agencies and practitioners ensuring all children have access to regular opportunities to share their concerns, regardless of their additional needs. In addition, disabled children's own perspectives about maltreatment have a crucial part to play in improving child protection practice with this group of children. Although, given what is known about the long-term consequences of maltreatment, it is also imperative that practitioners take heed of effective practice examples by working together and pooling resources to ensure disabled children's rights to protection are upheld.

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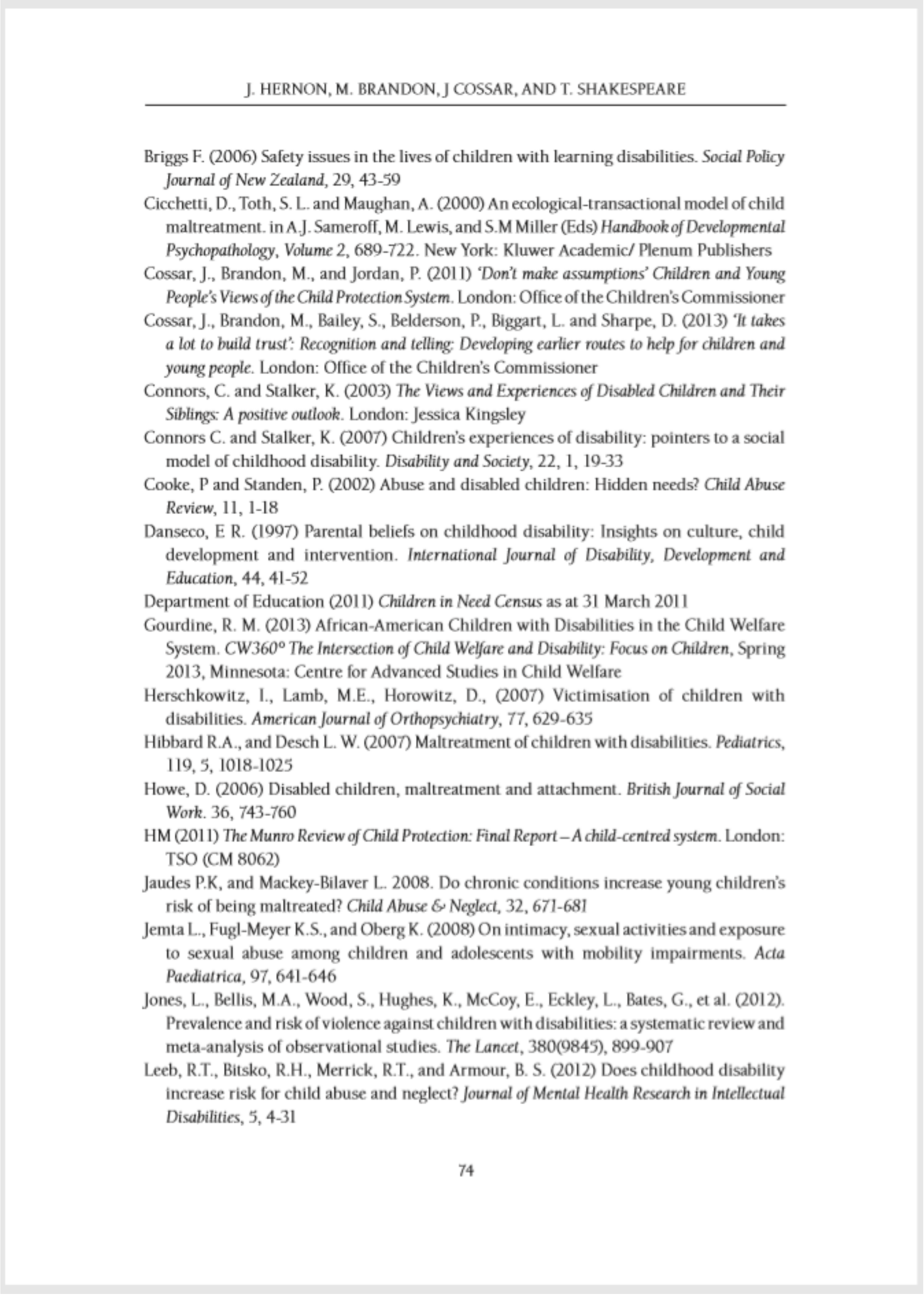

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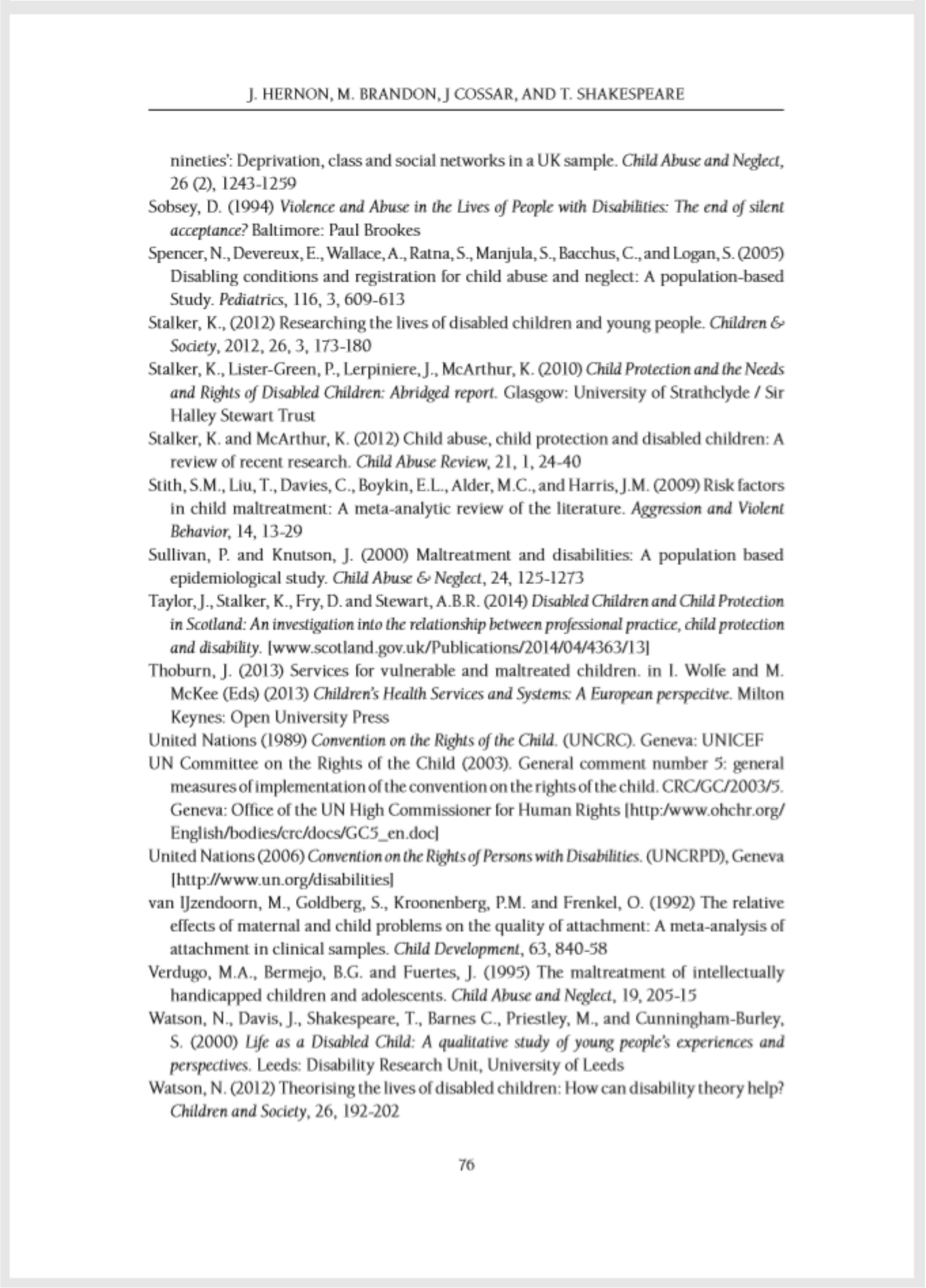

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Appendix 4

Participant Interview Question and Activity Matrix

Task/Question	Activity
Explaining study aims	Information Sheet
Gaining consent	Information sheet (written/audio) Consent form 1. Parent/Carer 2. Young Person (written/ symbol/verbal consent)
Setting ground rules Setting up recording equipment	Information sheet Stop-go card/ who's on the mic?
Getting to know you	e.g. My week tool to describe - your best day/activities/ routine
How do these young people see themselves within their families and wider social networks?	Who's in your world? Ecomap – buttons/stickers/figures/
How do these young people view their relationships with different professionals?	Helping people cards
What worries and concerns do these young people have? What or who helps them feel safe?	Worry people Helping people cards
What information and understanding do these young people have about being or having been the subject of a child protection plan? What are their experiences of being asked their views or of having decisions explained to them?	
What are these young people's views and experiences of having a social worker?	5 things about your social worker – outline of hand/points of a star
What would these young people like to be different in their lives?	Three wishes exercise
Conclusion and Debriefing	Debriefing sheet Concluding activity e.g. drawing/stickers/ iPad game/putty Thank you card/certificate/store voucher

Details of Questions and related Activities

Explaining study aims and gaining consent/assent

Information sheet and consent forms for young person and parent/carer

Setting ground rules

Before getting started participants will be:

- Able to familiarise themselves with the stop-go card and recording equipment.
- Asked if they are happy to carry on and start recording.

Getting to know you

I will start by showing young people the activity materials which will be stored in a box.

I will then give them the My week tool (Christensen and James (2008) to complete to tell me about their interest, what they like doing, about the school they go to, family routines.

How do these young people see themselves within their families and wider social networks?

I will ask participants to construct an eco-map, choosing stickers/ counters or figures on coloured paper or template of circles. These will represent and prompt discussion about the people closest to them.

I will use widget symbols or similar with young people with communication impairments/learning difficulties.

How do these young people view their relationships with different people, including professionals?

Participants relationships with the people in their lives represented in the eco-map will be further explored using helping people cards.

Helping people cards (Cossar, Brandon and Jordan 2011)

Photos or talking mat symbols will be used to explore participants views about the roles of different professionals in their lives.

What worries and concerns do these young people have? What or who helps them feel safe?

Young people will be asked to identify at least three things they are worried about or that concern them, using a worry doll to represent each worry (Cossar et al 2011)
Helping people cards will be used to discuss with participants who they might go to or tell about their worries or concerns.

What information and understanding do these young people have about being or having been the subject of a child protection plan? / What are their experiences of being asked their views or of having decisions explained to them?

Pots and beans activity (O'Kane 2008)

Thomas and O'Kane used this activity to explore the views of looked after young people about their involvement in review meetings but could be adapted to discuss participants experiences of being consulted and involved in decisions about being the subject of a child protection plan. A number of pots are labelled with a different aspect of being involved in decision-making. Within child protection process some suggested labels might be:

- How much are you asked what you think by professionals?
- How much are you listened to?
- How much do you know about why professionals come to see you?
- How much do you know about what happens at meeting?
- How much do you know about any decisions that have been made about you?

Young are asked to put up to three beans in each pot depending on whether they think each pot deserved where 3 = a lot, 2 = some, 1 = none, and asked to explain their choices. O'Kane (2008) reports this activity to be successful with children with learning difficulties owing, attributed to making abstract concepts more concrete and easier to understand.

What are these young people's views and experiences of having a social worker?

Participants will be specifically asked to list 5 things about their social worker e.g.:

Do they know the name of their social worker
Do they know why have a social worker?
What do they think about their social worker
How often do they see them?
Is it often enough?
What do they do together?

What would these young people like to be different in their lives?

Young People will be asked to identify things about their lives that they would change if they had three wishes. They will be given a magic lamp template to complete or a magic wand. If they have not mentioned the impact of their impairment on their everyday lives they will be asked specifically about this during this activity (Connors and Stalker 2003).

Conclusion and De-briefing

I will go through the information on the debriefing sheet with participants and thank them for their time and agreeing to take part (see Appendix 9). In recognition of the value of their time they will be given a thank you card, certificate and a £10 voucher. Participants will be offered to choose an informal activity to conclude the session, such as a game on the iPad, or craft activity.

Appendix 5

Parent Carer Interview schedule

Questions and prompts

1. **Thank very much for agreeing to talk to me, can you start by telling me a little bit about yourself and your family?**
   How many of you live here? Have you always lived in? How would you describe yourself as a family? What is important to you?

2. **Can you tell me a little bit about [young person's name]?**
   How would you describe their personality? What is important to them? What do they enjoy doing? How would you describe your relationship with them?

3. **I understand [young person's name] has a disability, can you tell me a little bit about that?**
   Do you feel it raises any particular issues for [young person's name]? Do you feel it has changed you as parent(s)/carer(s) and as a family, what has made things easier or harder?

4. **Can you tell me about your experiences of working with professionals to support [young person's name]?**
   Who has been most important/ help you the most? What would you have liked to have been done differently?

5. **Can you tell me about the support [young person's name] and your family has received from social workers and children's social care?**
   How did they get involved? In what ways has it been helpful or unhelpful? What is your experience of social workers? How would you describe their relationship with [young person's name]?

6. **Can you tell me a little bit about your family's experiences of child protection [or young person's experiences if living in care]?**
   What was your experience of the process, attending meetings? Did you feel your social worker/other professionals kept you and your child informed and listened to your views? How could things have been handled better? Do you think there needs to be a child protection system?

7. **Can you tell me about the support [*young person's name*] and your family are receiving from social workers now?**
   What has been helpful/unhelpful? What would you like to be different?

8. **What advice would you give to someone who was training to become a social worker?**

9. **What are your hopes for [young person's name]'s future and for all of you as a family?**

10. **Thanks very much for taking part, do you have anything you want to ask me about the project?**

Appendix 6

See me!Ask Me! Listen to me!

University of East Anglia

crcf
Centre for Research
on Children & Families

Equal Lives Youth Forum Terms of Reference

Aim

For my PhD research project, I want to find out what disabled young people think about having a social worker and receiving support during Child Protection.

I would like to involve Youth Forum members in helping to design and improve the activities and leaflets for use in interviews with young people.

What would be involved?

If the young people and Youth Forum Steering Group agree I would like to:

- Come along to a Youth Forum meeting to get young people's advice and suggestions on how to improve my research.

- Present some information about my project and briefly explain the child protection process and discuss research leaflets and activities.

- Visit again a few weeks later to get young people's feedback on the updated research materials.

- Involve young people in testing out and getting their feedback on the activities to be used during interviews

All Youth Forum members or a smaller group of volunteers would take part depending on group interest and views of the Youth Forum Steering Group.

Each session would last about an hour. Each young person will receive a £10 store voucher at the end of the second session to thank them for their time.

Consent, confidentiality and safeguarding

- Young people will receive written information about the project beforehand.

- Information about the project will be discussed at the start of sessions to check young people understand what they are being asked to do, are happy to take part and answer any questions.
- Young people can change their mind about taking part, leave the session or take a break at any time.

- The identity of all young people taking part will be kept confidential.
- Sessions will take place during scheduled Youth Forum meetings
- If any young person raises an issue of concern about their safety or that of another young person to Youth Forum support staff or myself, the researcher, appropriate action will be taken, and support offered according to Youth Forum Safeguarding Procedures.

Appendix 7

See me!Ask Me! Listen to me!

UEA
University of East Anglia

crcf
Centre for Research
on Children & Families

Equal Lives Youth Forum Information Sheet

Hello!

Thank you for letting me come and talk to you about my project

I want to hear your ideas about how to explain my project to young people and make taking part fun

There are 3 things I want to talk to you about:

1. Information for Young People about the Project
2. How to communicate with Young People
3. Questions and Activities for Young People

I would like to meet with you twice. The first time we will talk about Information for Young People and your ideas about good communication. If there is enough time we will do some activities.

In the second session I will show you the changes I've made to the Information for Young People. We will have a go at the activities and you can let me know what you think!

THANKS FOR TAKING PART

Appendix 8

Draft Project Flyer for Young People

See me! Ask me! Listen to me!

UEA
University of East Anglia

crcf
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on Children & Families

My name is Jane Hernon

I'm a PhD student at the

University of East Anglia

I would like to hear what you think about:

Being safe

Getting support

Saying what you think

You could help improve support for disabled young people

You will receive a £10 voucher

Interested? Please get in touch with your social worker

1. Flyer for Young People

Summary feedback on Flyer from Youth Forum Members (from notes made by Youth Forum Project Officer during session)

- More pictures
- Larger font
- PhD is not an understandable term, maybe use the term “project”
- A5 double sided on card picture on one side/ information on other
- Young people in logo picture too “young” – find one with older
- Include photo of UEA – Jane to bring some next time
- Use clearer picture of Jane
- Words hard to read on the blue background (comment from young person with visual impairment)
- Use same colours front and back
- Larger, clearer title
- More information about what the project involves
- Give contact details for Jane in case young person doesn’t want to go through their social worker
- Add easy read pictures

Appendix 9

Project Flyer following consultation with Equal Lives Youth Forum

UEA
University of East Anglia

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See us! Ask us! Listen to us!

Are you a disabled young person aged 11-18?

See us! Ask us! Listen to us!

My name is Jane Hernon

I am a student at the University of East Anglia

I would like to hear what you think about....

❑Having a social worker

❑Being Listened to

❑Keeping safe

You could help improve support for disabled young people and their families

You will receive a £10 voucher

Interested? Please contact me or your social worker

☎ ✉ @

07741 123572
J.Hernon@uea.ac.uk

Appendix 10

Draft Information sheet for Young People (Easy read)

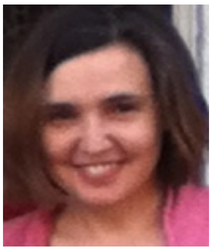
See me!Ask Me! Listen to me!

University of East Anglia

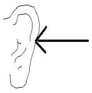
Centre for Research
on Children & Families

See me! Ask me! Listen to me!

My name is Jane Hernon. I am a PhD student at the University of East Anglia

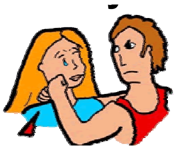


I would really like to hear about your ideas and thoughts about the help you get with keeping safe

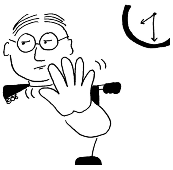


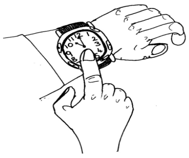
Our talk will be in private, I won't tell anyone what you said

Unless you tell me you or someone else is not safe and needs help.

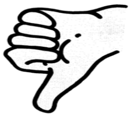


You can ask for the interview to stop at any time. It will take no longer than one hour.





You can say yes or no. It is up to you whether you take part.



If you do want to take part, please ask someone to help you read the form

If you would like to talk to me, I would be very grateful if you could sign the attached form and return it.

Taking part is your chance to say what you think. You will receive a £10 voucher for your time

If you would like to know more about the project, please contact me by post, by telephone, or by email.

School of Social Work UEA, Norwich NR4 7TJ	01603 592068 9.30am – 5 pm	J.Hernon@uea.co.uk

Thank you for taking the time to read this letter and for your help.

☺

Summary feedback on Flyer from Youth Forum Members (from notes made by Youth Forum Project Officer during session)

- Picture about not being safe isn’t clear – add thought bubble and include easy read symbol about asking for help
- Include 2 or 3 pictures about keeping information private
- Would be better if all of the pictures were in colour (draft only has a little bit of colour
- Put the easy-read symbols in boxes like in the Youth Forum Referral Form (example provided)
- Have picture of a no entry sign with no names underneath as well as picture of a file with a lock on it
- Include picture of stop sign and of a cup of tea to represent taking a break
- Comments on logo and clearer picture of Jane etc as for Flyer

Appendix 11

Information sheet for Young People (easy read) following consultation with Equal Lives Youth Forum

See us !Ssk Us! Listen to us!

University of East Anglia

crcf
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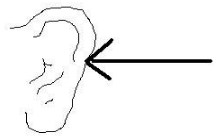
on Children & Families

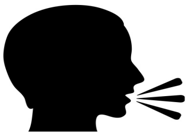
My name is Jane Hernon. I would like your help with my project.

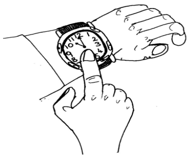
I want to hear what you and your family think about young people, disability, getting help from social workers and feeling safe

		 ~~No names~~

Our talk will be in private, I won't tell anyone what you said

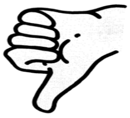
Unless you tell me you or someone else is not safe and needs help

 1 hour		

Our talk should take about an hour, but you can stop or take a break at any time.

This is a chance for you to have your say. You could help improve support for young people. You will be offered a £10 voucher

You can say yes or no. It is your choice to take part or not

✉ **Centre for Research on Children and Families UEA, Norwich NR4 7TJ**	📱 **07741123572**	@ **J.Hernon@uea.co.uk**

Want to take part? Please contact me or your social worker

THANKS!

☺

Appendix 12

Fieldnotes and reflections on pilot interview with Nicola

Notes on Methods - What worked well?

Nicola was able to talk well, although I found some of her words difficult to understand.

Information sheet/ consent form
Nicola seemed to be happy to speak to me. She remembered my photo from the information sheet and that the project was about listening and having social workers.

Nicola seemed able to understand easy read consent form (helped confirm appropriate level for young person with moderate learning difficulties). Having seen information sheet before, which is quite similar, seemed to help. Nicola asked questions about being recorded but although she was anxious about it at first seemed to forget about the tape recorder after a while

Hand activity didn't work so well as led Nicola to comment "I can't write properly", so I suggested she drew instead as I didn't want to undermine her confidence or take over by writing for her. Could perhaps extend using widget symbols of feeling faces with other young people who struggle with writing.

Helping people cards prompted useful discussion around Nicola's support network and relationships with different professionals (e.g. police, carer, remembered her support worker. Nicola also said she liked the cards, thought photos worked better than pictures (had asked for photo of her social worker, but no reply – too busy?)

Ecomap worked well – although I felt blank paper might have worked better perhaps, as felt template limited discussion. Although it was interesting how Nicola used circles to group people together e.g. brothers, sisters, teacher and social worker v Bronfenbrenner! Also highlighted lack of friends??

My week tool – using widget symbols worked well (avoided need for writing – see above). Nicola lit up when talked about riding and music, and seemed to enjoy opportunity to talk about her interests, club, also prompted discussion about been being bored at home and wanting to visit home town (placed out of area fits with findings of other studies)

3 wishes – was dubious at first and felt should perhaps have left it out as Nicola was in care, however it prompted a useful discussion about wishing she was back with Mum (despite seeming accepting of reasons she is in care)

Reflections after listening back to recording

The first part of the interview was in her teachers' office alone. Half way through we moved into the classroom while J ate lunch. With hindsight moving into the classroom was unhelpful as it: 1. Broke the flow of the interview 2. Was a more public space as although we were alone the teaching assistant coming in and out which at times inhibited me from asking personal questions and Nicola also seemed more anxious after we were interrupted. On reflection would be helpful to try and do most interviews with YP at home if possible. Interviewing at school meant I was unable to clarify/confirm issues with Nicola's carer e.g. how long in current placement? which Nicola was less clear about.

Despite the less than ideal environment and interruptions Nicola was able to express herself well and was mostly animated and engaged when speaking. She seemed quite accepting of not being with Mum but ambivalent – kept coming back to it and talked also about her sisters – but also repeated 2 or three times CP had been a good thing. Seemed sad wasn't with her sisters and seemed to lack close relationships.

As a researcher I had difficulties being relaxed asking open ended questions. I felt I did too much reflecting back what Nicola had said with possibly a risk of putting words in her mouth. Diid not always pick up on J's cues eg about police being helpful and could have explored this issue in more detail.

Reflecting back this may have been a result of my focus on making things OK for Nicola (perhaps because I am used to being a practitioner, and felt a sense of responsibility not to upset her). Although this was important in ethical/ moral terms it also meant that some opportunities to explore issues and possibly gather richer data were missed. Also a few times I interrupted Nicola and this closing down some of her answers and possible opportunities to expand on some issues. This meant some of her responses were more stilted than otherwise might have been.

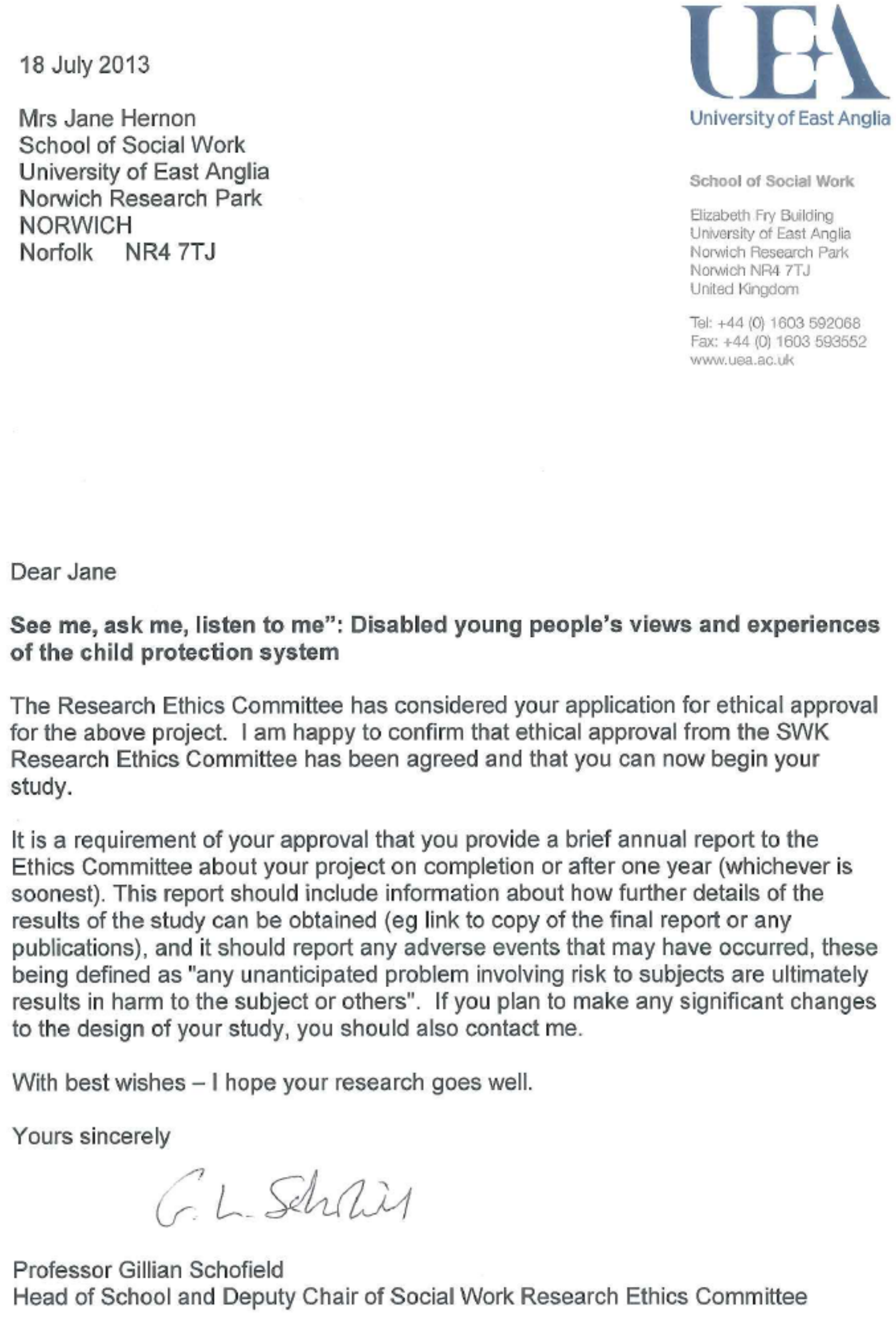
Overall, I felt Nicola was a relatively straightforward young person to interview. Apart from time lag answering questions (perhaps due to learning difficulties) she had clear views about child protection and in some ways the fact this experience was some time in the past perhaps meant this experience was less raw and this may have contributed to Nicola being more able to talk about/ reflect on meaning of the process in her life as a whole.

Next steps

- Need to decide how going to tweak interview materials. Overall tried and tested worked best. Some will depend on individual young person, speaking to parent/ carer beforehand)
- Need to focus on asking more open-ended questions e.g. can you give me an example, and allowing young person time to answer fully and resist interrupting

Appendix 13

Letter from Research Ethics Committee confirming the study's ethical approval



UEA
University of East Anglia

School of Social Work

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

Tel: +44 (0) 1603 592068
Fax: +44 (0) 1603 593552
www.uea.ac.uk

18 July 2013

Mrs Jane Hernon
School of Social Work
University of East Anglia
Norwich Research Park
NORWICH
Norfolk NR4 7TJ

Dear Jane

See me, ask me, listen to me": Disabled young people's views and experiences of the child protection system

The Research Ethics Committee has considered your application for ethical approval for the above project. I am happy to confirm that ethical approval from the SWK Research Ethics Committee has been agreed and that you can now begin your study.

It is a requirement of your approval that you provide a brief annual report to the Ethics Committee about your project on completion or after one year (whichever is soonest). This report should include information about how further details of the results of the study can be obtained (eg link to copy of the final report or any publications), and it should report any adverse events that may have occurred, these being defined as "any unanticipated problem involving risk to subjects are ultimately results in harm to the subject or others". If you plan to make any significant changes to the design of your study, you should also contact me.

With best wishes – I hope your research goes well.

Yours sincerely

G. L. Schofield

Professor Gillian Schofield
Head of School and Deputy Chair of Social Work Research Ethics Committee

Appendix 14

Debriefing Sheet

See me! Ask me! Listen to me!

University of East Anglia

crcf Centre for Research on Children & Families

Debriefing Sheet
This project is trying to find out what disabled young people think about:

Having a social worker	Being Listened to	Keeping safe

It is being carried out by Jane Hernon at the University of East Anglia.

If you want to complain about the way the interview was carried out contact: Gill Schofield, School of Social Work, University of East Anglia, Norwich, NR4 7TJ, g.schofield@uea.ac.uk: Tel.: (01603) 592068.

If you want to speak to someone about anything else please contact your social worker or one of the organisations on the opposite page.

If you would like one I will send you a leaflet explaining what the research project has found out about young people like you.

THANK YOU FOR TAKING PART !

Organisations who may be able to help you

ChildLine 0800 1111

Tel 0800 1111

www.childline.org.uk

Free to call. Available 24/7. Call if you're feeling scared, stressed or just want someone to talk to.

ecdp

Tel 01245 392 300

www.ecop.org.uk

Support and for disabled people of all ages.

Papworth Trust Equality Choice Independence

Papworth Trust runs youth clubs in Essex for disabled young people (aged 11 and over)

Tel 0800 952 5000

Email info@papworth.org.uk

Essex County Council

Family Information Service
Tel: 0800 055 6874

Information on local services for young people.

Protection for Children and Adults Helpline
Tel: 0845 606 1212

If you are concerned about your safety or that of another young person

Appendix 15

Information Sheet for parents and carers

See us! Ask us! Listen to us! – Information for parents & carers

Who am I?
My name is Jane Hernon. I am a research student at the University of East Anglia

What is my project about?
My project is trying to find out what disabled young people and their families think about their lives and their involvement with Services.

This is because families like yours have had few opportunities to talk to researchers about their views. Giving families a chance to have their say about what they found helpful or unhelpful is an important part of helping to improve services.

What will happen if we take part?
If your family agrees to take part I will:

- Come and talk to you about the project
- Spend some time with you and your child on you own listening to your views
- The visit will take about 1 ½ hours but I can come back if you need longer to talk

What will you talk to us about?
I will talk to you each of you about:

- Growing up with a disability/ bringing up a disabled child
- Having a social worker and receiving services

Can I change my mind, stop or take a break if I want?
It's your choice whether or not you want to take part in the project, and you or your child can change your mind at any time.

There are no right or wrong answers, you don't have to answer every question. You can take a break or stop at any time.

How long will it take?
The visit will take about an hour, but we can take as long as we need to talk, or I can come back and see you again.

Will you understand what I say?
It is important that we are able to understand each other. I will talk to you and your child about whether we might need any help before we start.

How will you remember what I say?
I would like to record what we talk about rather than writing things down so that I can concentrate on what you are saying.

Who will you tell what I've said?
What you say will be kept confidential. This means if I write about anything you or your child say in my report, I will change your names so no-one will know that it was you who said it.

The only time I might have to share your information is if you or your child say something that makes me concerned that they or another young person is not safe.
If I need to do this I will always try and tell you first, but sometimes I might not be able to.

What's in it for us?
Taking part is a chance for you to say what you think about the help your child and family gets with keeping safe. What you say may help improve support for other families.

You and your child will receive a £10 store voucher for your time.

If you have any questions about the research please contact me: Tel: **07741 123572** or email: J.Hernon@uea.ac.uk

Appendix 16

Agreement form for Young Person (Easy read)

See us! Ask us! Listen to us!

University of East Anglia

crcf
Centre for Research
on Children & Families

Young Person's Agreement Form

If I talk to Jane about my experiences

- I understand that our talk will be recorded.

- I understand that our talk will be private.

		 ~~No names~~

- I understand that I can stop or take a break at any time.

If you understand the statements above, you now need to decide whether you would like to take part in the project.

I have decided that I would like to talk to take part

Please put a circle round No or Yes.

☒ No

☑ Yes

Signed…………………………………………

Please print your name………………………

Appendix 17

Consent form for parents and carers

See me!Ask Me! Listen to me!

University of East Anglia

crcf
Centre for Research
on Children & Families

See me! Ask me! Listen to me!

Parent/carer Consent Form

Please tick

☐ I have read the information leaflet

☐ The research has been explained to me and my child

☐ I agree for my child to take part in the project

☐ I agree for my child's interview/s to be recorded.

☐ I understand my child can leave the project at any time if they/we change our mind.

☐ I understand that my child's name will not be used and that they will not be identified in any way in the report.

Name ……………………………………… Date:

Signed ……………………………………… Date:

Childs' Name ………………………………………

Appendix 18

Study information for managers and social workers

See us! Ask us! Listen to us!

University of East Anglia

crcf
Centre for Research
on Children & Families

See us! Ask us! Listen to us! Disabled young people and their families' views about Child Protection Services.

My name is Jane Hernon. My PhD research explores disabled young people and their families' experiences of living with disability and their views about their involvement with Children's Safeguarding Services.

I am supervised by Professors Marian Brandon and Gillian Schofield, in the Centre for Research on Children and Families, at the University of East Anglia.

Project Aims

The Munro Review of the Child Protection System (HM 2011) called for greater focus on the views and experiences of children themselves and emphasised their right to be involved in decision-making[1].

There is a growing literature on this topic[2], but few studies seeking the views of disabled children and their families.

This is an important gap in knowledge given research consistently identifies disabled children as being 3 to 4 times more likely to experience abuse.[3] Little is known about how well safeguarding services in the UK respond to the needs of disabled children and their families[4].

My project aims to explore disabled young people and their family's views about their lives and their experiences of children's services involvement, e.g.

- Growing up with a disability / Bringing up a disabled child
- Knowledge and understanding of the child protection system
- Being asked their views or having decisions explained to them
- Priorities for support

Methods

- I wish to interview disabled young people aged 11-18 and their families, currently or previously the subject of a Child Protection Plan.
- Young people in care, previously the subject of a Child Protection Plan

---

[1] UNCRC (1989), Children Act (1989)
[2] Cossar, Brandon and Jordan (2011), Woolfson et al (2010)
[3] Jones et al (2012)
[4] Stalker and McArthur (2010)

- I aim to recruit 20-25 disabled young people and their families via 3 Local Authorities.

Consent

Young people who agree to take part will have consented willingly, after I have explained to them and their parent or carer[5] that:

- The interview will be recorded
- Their identity will be kept confidential[6]
- They can withdraw from the study at any time.

Interviews

- I will visit young people and their families in their homes (or location of their choice) on one or two occasions.
- Parents and young people will be interviewed separately about their views and experiences.
- Young people will take part in activity-based interviews[7] to help them express their views about their lives and receiving support.

Project Benefits

- Each young person and their caregiver will be offered a £10 store voucher for their time and a summary of project findings.
- Project findings will be presented to practitioners and managers in each local authority, who will be sent copies of project reports / articles.

Project Findings

It is hoped project findings will:

- Add to current knowledge about disabled young people and their families' experiences of the child protection process
- Identify and promote good practice
- Improve practice and policy responses towards disabled young people and their families

For more information or for a discussion about the project please contact me

✉	☎	@
Centre for Research on Children and Families UEA, Norwich NR4 7TJ	**Tel: 07741 123572**	**J.Hernon@uea.ac.uk**

---

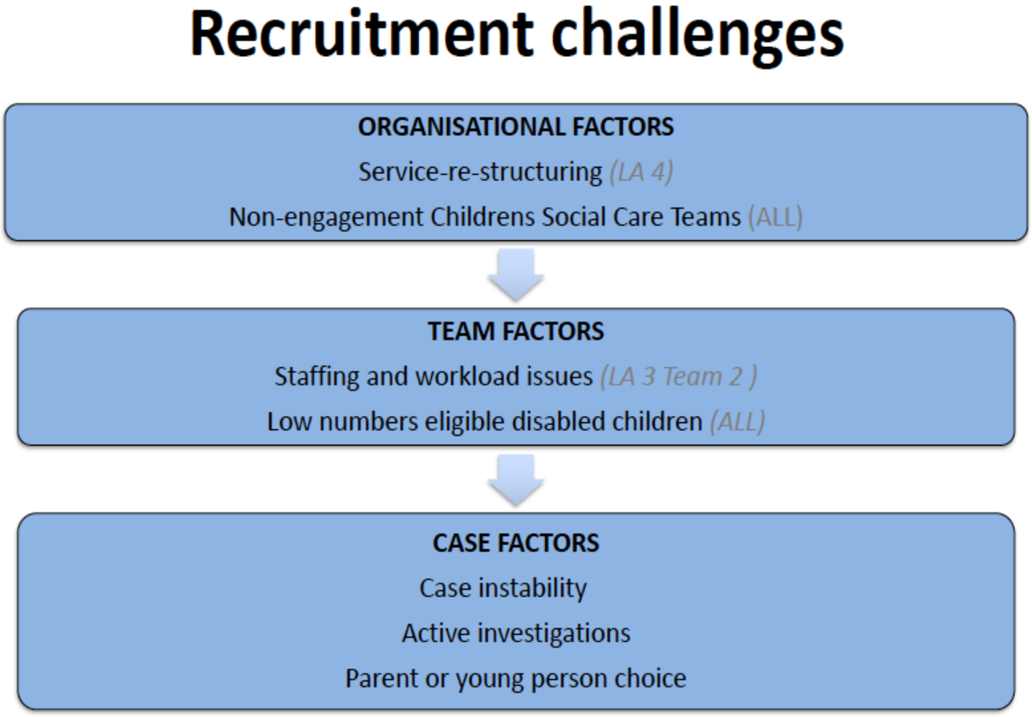
[5] The young person's parent/carer will also be required to give their consent

[6] Except where the young person indicates that they or another young person is at risk of harm. A protocol for reporting such concerns to the Local Authority will be agreed at the start of the project

[7] Activities will be tailored to young people's learning and communication needs

Appendix 19

Recruitment challenges and enablers



Recruitment challenges

ORGANISATIONAL FACTORS

Service-re-structuring *(LA 4)*

Non-engagement Childrens Social Care Teams (ALL)

TEAM FACTORS

Staffing and workload issues *(LA 3 Team 2)*

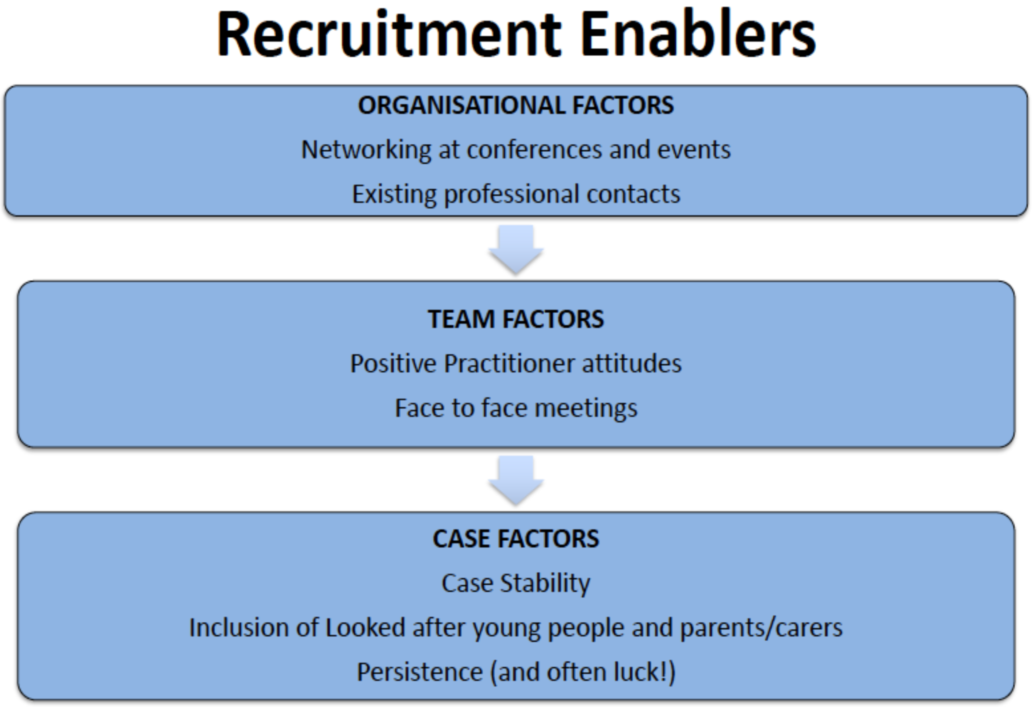
Low numbers eligible disabled children *(ALL)*

CASE FACTORS

Case instability

Active investigations

Parent or young person choice



Recruitment Enablers

ORGANISATIONAL FACTORS

Networking at conferences and events

Existing professional contacts

TEAM FACTORS

Positive Practitioner attitudes

Face to face meetings

CASE FACTORS

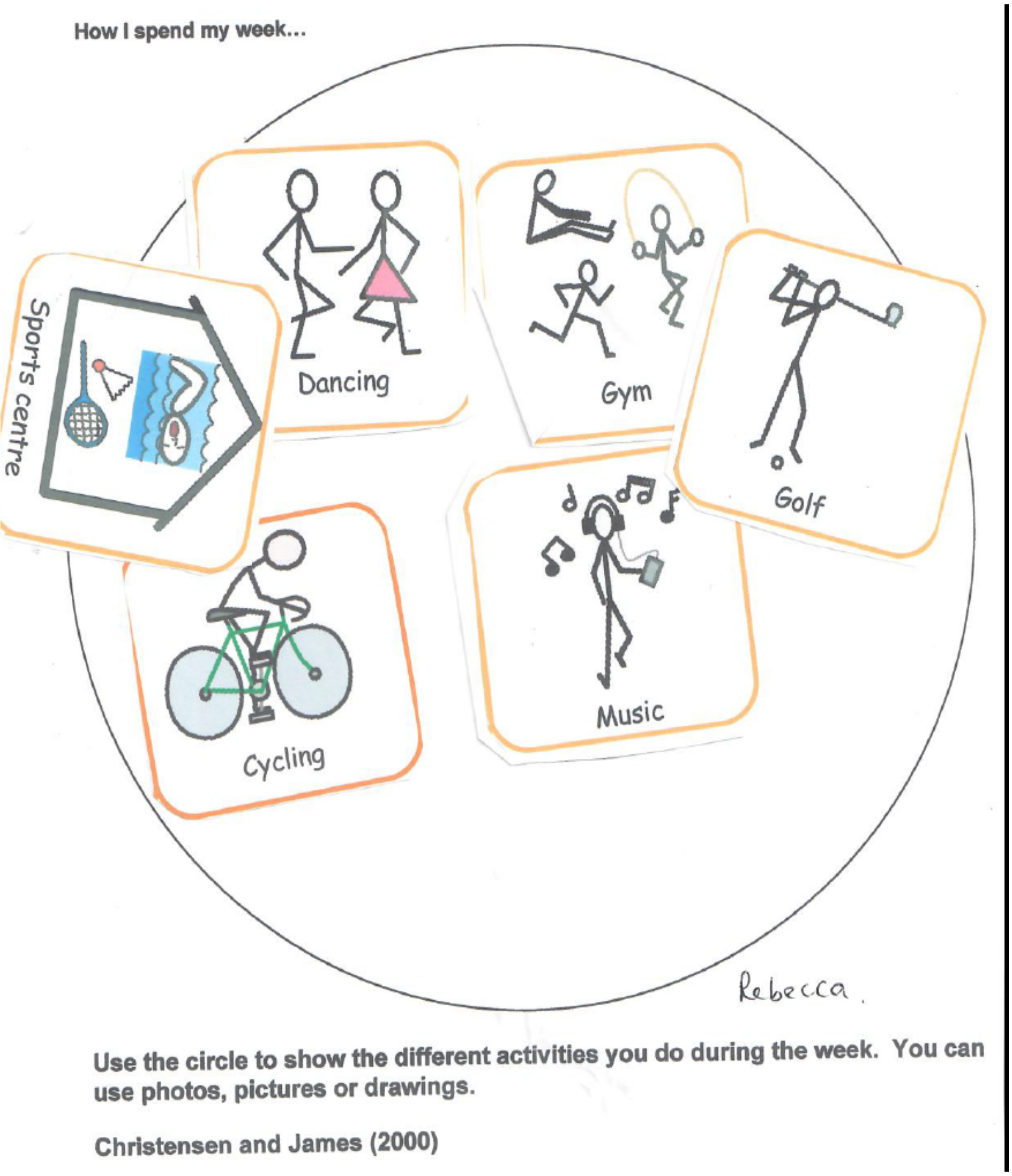
Case Stability

Inclusion of Looked after young people and parents/carers

Persistence (and often luck!)

Appendix 20

Example of my week tool (completed by Rebecca)



How I spend my week…

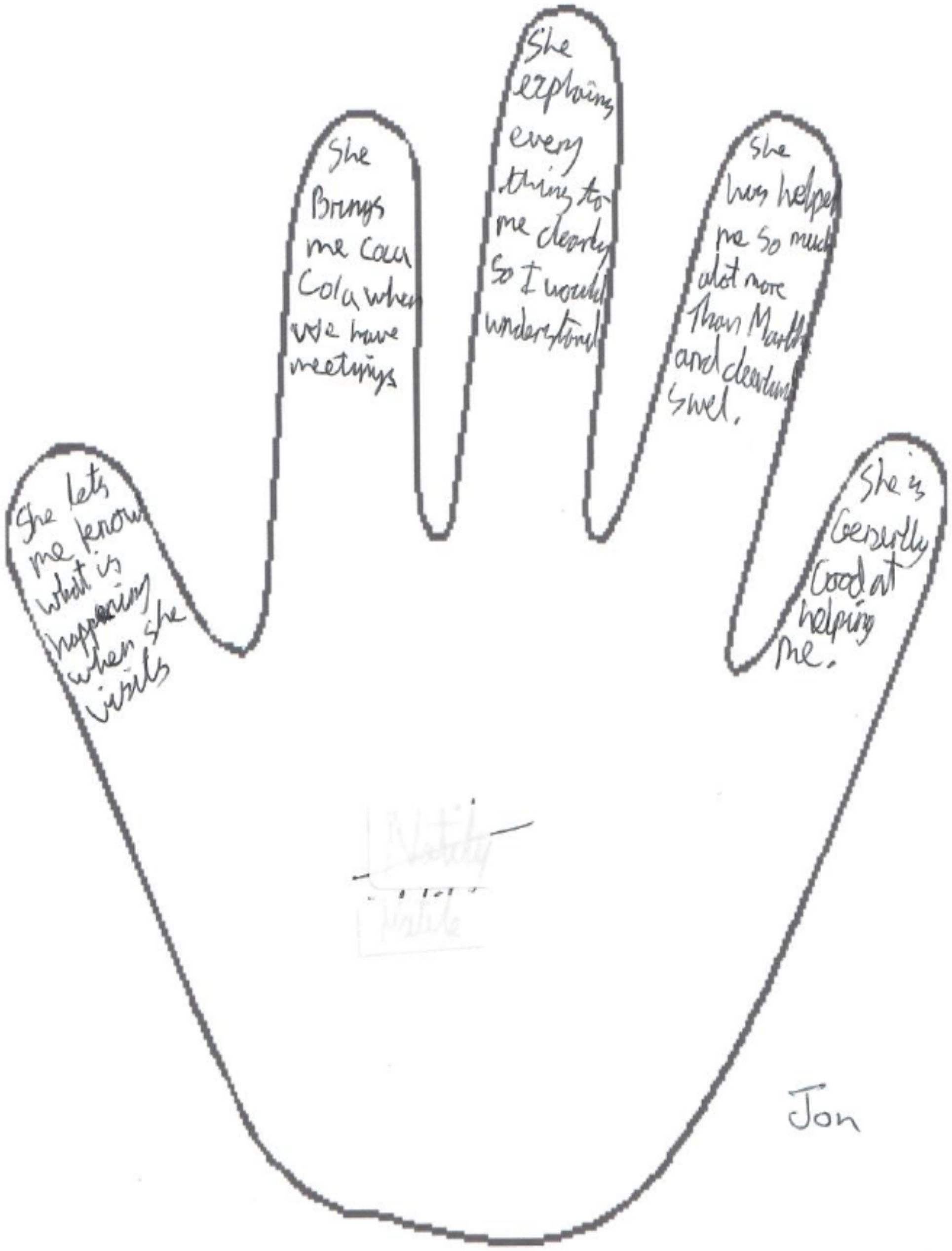
Rebecca.

Use the circle to show the different activities you do during the week. You can use photos, pictures or drawings.

Christensen and James (2000)

Appendix 21

Example of 5 things about your social worker (Hand tool) – completed by Jon



She lets me know what is happening when she visits

She Brings me Coca Cola when we have meetings

She explains every thing to me clearly So I would understand

She has helped me So much alot more than Martha and dealing swel.

She is Generally Good at helping me.

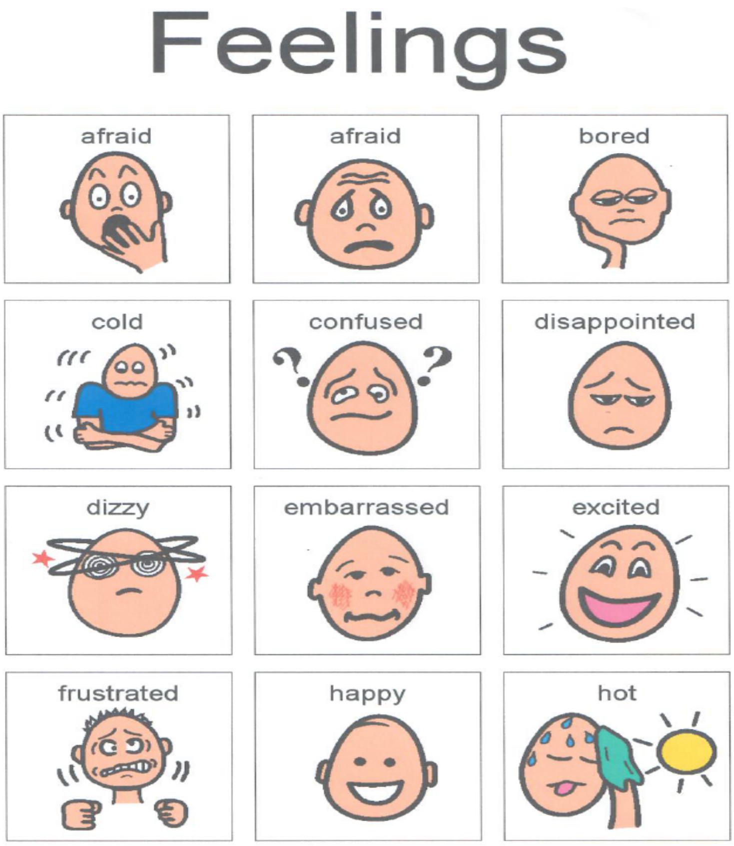
[redacted]

Jon

5 things about your Social Worker (Thomas and Kane 1998)

Appendix 22

Ecomap activity and ‘feelings’ faces used in interview with Ben (adapted from communication passport at Short Breaks Unit)



Appendix 23

Questions used to guide writing of fieldnotes

Fieldnotes were completed as soon as possible after the interview. Questions considered included:

1. What was the family home/residential placement like? What were relationships like between participant and his or her caregivers, any siblings or other staff or young people like?
2. What went well/ what didn't go so well?
3. What issues could have been explored further? Including possible reasons contributed to this not happening
4. Did any unexpected difficulties arise during the interview (were participants upset/ angry/ were their issues of potential concern, including whether these need to be passed on/discussed with supervisor?
5. What were the main things that were important to this participant?
6. In what ways were the issues this participant raised similar or different to previous participants?

Appendix 24

Example Fieldnote (following interview with Liam)

What was the home like?
My initial impressions were that the bungalows although modern looked drab and a bit depressing. Arrived to be greeted by a YP who turned out to be Liam and the duty manager. He said hello and she asked to see ID. She then showed me into the lounge. The atmosphere seemed relatively homely, apart from interjections about routine and staff arrangements.

Relationships with staff
I asked the staff about Liam and did they know him well. One had been working there three months the other two. I joked that you get to know the ropes quickly. The female staff member explained that she had previously worked with adults with learning disability/challenging behaviour. She commented that the main differences were with children you had to write more down, you were allowed to restrain young people (adding that this was only as a last resort, after talking down, using incentives etc) and the pay was better. I explained I had spoken to a member of staff) and home manager previously about arranging the visit – both have now left and apparently the locality manager is also leaving in 2 months. The duty manager also later said she did not often work in that unit – although had clearly worked for the agency for some time as Liam remembered her being on shift 4 years ago the day he had first arrived at EC as an emergency (this seemed important to Liam and very poignant memory for him).

I checked out with staff about asking Liam about his family as was aware the background was complex and he had very limited contact. They confirmed he has contact only with his older brother. Staff said he did not have contact with his sister because of allegations he had abused her in the past. They said he rarely talks about his family but will sometimes mention Mum and Dad when upset. He has also talked about things that have happened at home, which staff write down in case this is new evidence. The member of staff commented that it was hard to know whether it was all true or if Liam was making some of it up. I found this interesting (a common dilemma) and also troubling.

What went well/ not so well
Liam then joined us so I was unable to explore what she meant. I found it hard to guage Liam's level of understanding at first as he said little. This was probably because I was trying to explain the project and gain agreement but Liam also seemed nervous at first. I used the symbol based information sheet – and did ask if Liam if he could read – his literacy seemed at a fairly basic level, although he was able to write his own name, read helping people cards, etc but pictures still seemed more appropriate, also chose the simpler stop/go/not sure cards

Liam was Ok to agree and I introduced the activities. Liam cleared the table which I took to indicate his willingness to engage – but still said very little – prompts from staff helped with this and as in earlier interview with another young person helped me relax and to pitch the interview questions at the right level. It is a process of trial and error and hard at times to avoid being patronising. At times staff contradicted him, interrupted but he also engaged them by asking questions. I felt his answers would have been more stilted if staff had not been present – interesting parallels in context of literature on involving staff who are well known to YP aiding communication/ rapport building. Liam did have a mild speech impairment but was mostly fairly easy to understand and also patient.

Staff being present also allowed me to observe a clearer sense of Liam's position within the home and his relationship with staff. He seemed very confident as indicated by his comments and behaviour during the interview, however other behavioural traits, adjusting pen position (when this was in my space, needing to be involved in decisions about seating arrangements suggested to me his agency might be bordering on controlling related to underlying anxiety?? – more positively may also indicate he feel able to exert agency with staff and feels "at home and part of the team – staff seemed to suggest he responds fairly well to boundaries (given he has challenging behaviour) and seemed genuinely OK with incentives system.

Humour worked well as a strategy for maintaining/ creating engagement and felt reciprocal – diffuses power/ interest imbalance

What issues could have been explored further? (possible reasons why)
Liam's answers were mostly fairly short perhaps partly due to his mild communication issues? I was reluctant to probe further about the CP process, as he has vivid memories of being removed from home by the police. It is still interesting, however that he said did not see SW as having a part in his removal but this may indicate his concrete thinking because of his LDs – asking him about CP conferences may have helped, however he also could not recall the previous Sws name, although she did seem important to him.

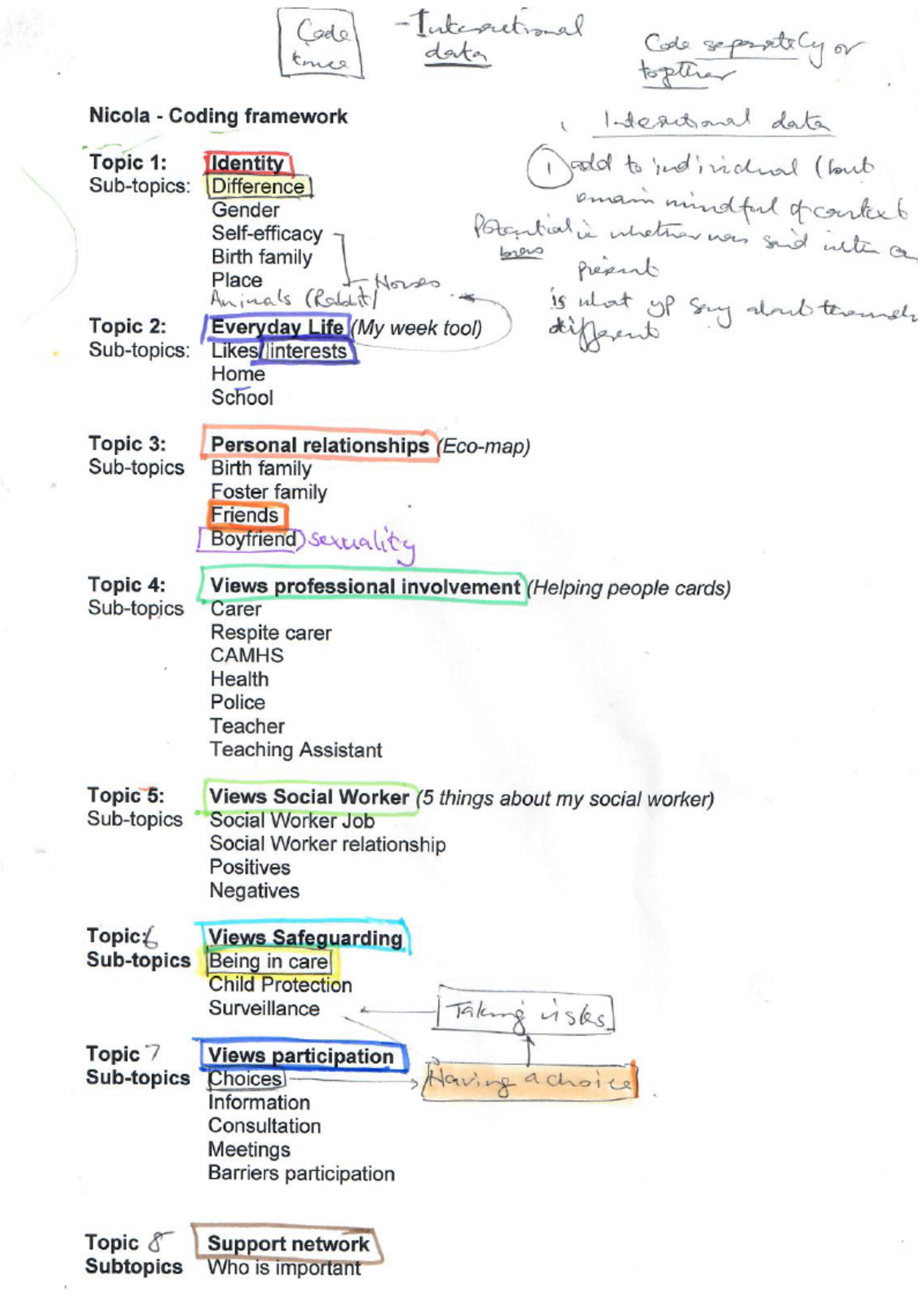
What was important to Liam?
Liam appeared to value the good relationship with his current social worker and how she involves him in meetings/ spends time getting to know him.

Liam was very distractable during the interview – seemed to have a strong need to know what was going on, also wanted to get to Post office to buy a pepsi – and seemed increasingly bored/ tired towards the end of the interview so needed to stop. Lacked any clear sense of the future be simply because he is 14? Joked when saying goodbye that Liam needed to "look after the staff' he said he would make sure they behaved – he seemed to like this as after this he shook my hand to say goodbye which seemed to me perhaps to suggest he appreciate me respecting him and his 'agency'.

Similarities and differences with other participants
Other younger participants have also given less of a sense of what they want to do than those in transition). Liam gave a similar account to Hannah about chairing his Looked after children's meetings, asking questions of etc – contrasts with other participants accounts of child protection meetings. Appeared to value clear boundaries from staff in managing challenging behaviour similar to another participant talking about her carer restricting access to her iPad.

Appendix 25

Developing a Coding framework



Code twice

- Intersectional data

Code separately or together

Nicola - Coding framework

Intersectional data

① add to individual (but remain mindful of context

Potential bias i.e. whether was said with a present

is what YP say about themselves different

Topic 1: **Identity**
Sub-topics: Difference
Gender
Self-efficacy
Birth family
Place
Animals (Rabbit) – Horses

Topic 2: **Everyday Life** *(My week tool)*
Sub-topics: Likes/interests
Home
School

Topic 3: **Personal relationships** *(Eco-map)*
Sub-topics
Birth family
Foster family
Friends
Boyfriend Sexuality

Topic 4: **Views professional involvement** *(Helping people cards)*
Sub-topics
Carer
Respite carer
CAMHS
Health
Police
Teacher
Teaching Assistant

Topic 5: **Views Social Worker** *(5 things about my social worker)*
Sub-topics
Social Worker Job
Social Worker relationship
Positives
Negatives

Topic 6
Sub-topics
Views Safeguarding
Being in care
Child Protection
Surveillance ← Taking risks

Topic 7
Sub-topics
Views participation
Choices → Having a choice
Information
Consultation
Meetings
Barriers participation

Topic 8
Subtopics
Support network
Who is important

Agency
Controlled him
not ask.

2 new friends Lazy – Hamish
Discovery –
When days like.
That's so rude!

Change of [illegible]
dad
Need a friend
– Boyfriend
He's too bossy
Controlling

Jo's it
every year
– 1hr.
– 1hr car.
– 1hr together.
Additional
ISA
Work Older people } Caring role.

School, transport
– Jon
– Younger ones Jack

What is important
Who helps

Topic 9 . **Wishes and Aspirations** *(Three wishes tool)*
Aspirations
Dreams
Wishes

Topic 10. Transitions – Weird / Scared.
Change
3 friends
I used to have loads : [redacted]
Annabel – nervous
I don't know
I got there in the end
[redacted] – "like a big kid".

– It doesn't bother me
– He only talks to diness adult
Boyfriend,
– He likes seeing [illegible]
"He's not good [illegible] own person"
Nicola } It's awkward

Interests
Ice-skating –
Dogs
– like animals.

Consistency!
All these changes! "left to last minute" – Last planning – Transport
Have to carry it.
Losses
– Annoying
Falling asleep in car.

Keeping safe / sensible
Teachers, Trust] I wouldn't do that

Freedom –
ASDA – Fizzy 20-25 walk.
Bike

Safe by Phone

Foster Sister
Nicola She needs to be pushed out the door sometimes
– Peace, quiet [redacted]
[redacted] Always safe when someone has boundaries.

Self.
Negative / Can't read
"Moving" School
Same building
Emotions "I just get angry" – "Big struggle for me", I do miss my friends
Boring in car.
Confusing
Annoyed.
"Boundaries" can't stand her cos she don't go anywhere!
Street dance.
Lap-top watching films
Worldsaver –

Developing Independent – Local. Community – Specialist

Nicola / Give it a try

Appendix 26

Example Memo

Reflections on Impact of being disabled and in care away from where birth family live (interviews with Liam and Nicola)

Having looked at Liam and Nicola's interviews I have observed similarities and differences in terms of these young people's experiences of agency/participation and levels of surveillance and impact of living away from , which may or may not also be found in other interviews?? (e.g. Hannah?)

Humour – Agency?
Firstly humour is used a great deal, by both participant and others present (myself as researcher) and carers (Liam). Reflecting on this it appears that humour has a number of different purposes and meanings across both interviews.

Thoughts on this include:
1. Demonstrating agency/ asserting control e.g." I'm not having a debate about it", "open til te-er-n" "Let me tell you"
2. Marking a boundary
3. Means of engagement "did you sort them out?"
4. Negotiating shared meaning
5. Gaining attention "you're my favourite you are" "sau-sages"
6. Avoiding or deflecting painful realities I haven't: I burnt it (Liam), Isn't that a bit too much now (Nicola)

Names significance, living in the present or avoiding pain e.g. Liam?
Both participants appear more likely to use names when the relationship or place is of greater significance - although their are exceptions, e.g.s where use of name or not seems more likely to indicate "concrete living in the present" or perhaps to avoid difficult topic e.g. Mum and Dad mentioned by Liam once (Hannah also explicit about not wanting talk Mum and Dad)

e.g. Nicola mentions Stevie unprompted twice but other sisters only once. Doesn't mention town or county she lives in once, but mentions London borough and area birth family live several times.

e.g. Liam does not use carers names, apart from favourites, doesn't mention previous SW name - although say she is nice rather than just OK

During discussion about going to the football to see Local team play says (where f hell is that?) but when talking about City where family live (I haven't: I burnt it), nearest larger city football team says don't know much about them)

Participation

Nicola is frustrated by her lack of ability to influence decisions although she is confident in expressing her views but seems to "know" also when it is worth making a stand. She seems to expect to be thwarted in some areas, though difficult to know if this is realistic - example of wanting to live with her sisters although this clearly important to her identity seems to accept/not expect that this dream "will come true" - Low aspirations

Nicola able to make everyday choices but several examples of her ability to influence even everyday decisions strong sense of "requiring permission" e.g. hope they might let me go outside" or depending on others availability it's up to the foster carers. Sense of being in care of supervised contact as proscribing family, but also other relationships e.g. boyfriend but not clear if this is to do with disability or being in care - seem to operate in similar way e.g. Nicola talking about disliking being popular, everyone says I'm special - but amount of attention coming into care could also be what she means as school mentioned is a special school where most of the pupils had similar level of LDs. But not aware of specific sense of "looked after" identity in relation to peers being mentioned by any of the participants.

Conversely Liam doesn't express same level of frustration, despite needing greater "permission" to do what he wants. Seems to value "incentives" system, as becomes quite animated at this point having been largely unresponsive during the interview up until this point, sees this as a way of getting what he wants "I need to earn it so I can go to the Post Office". He also doesn't bat an eyelid when the carer asks what he wants for breakfast and in fact gives more detail than required - "with choc-o-late. Other instances more suggest a need to be in control e.g. tuning in and disappearing whenever something happens or other conversations, knowing how many tins of spaghetti are in the cupboard, trying to dictate seating arrangements on the trip to collect the company vehicle, needing to know the time so he doesn't miss out on his post office trip. Also important to keep in mind his adolescence - but many adolescence equally resist intrusion - some evidence of this also - contradicting things carers put forward e.g. swimming, city football shirt.

Liam also confident about influencing decisions made at LAC reviews and his comment Who makes decisions "Me and my social workers" - although ironically his ability to participate in the world out there and also to some extent in the unit are heavily censored (most 14 year olds, even those in care wouldn't think twice about a trip to the shops, at most they might tell you them were going (unless they needed a lift, but he says "up the road" - but framed by other carer's comment "I don't want him just wandering off" indicate the level of censure Liam experiences - but he himself appears minimally frustrated by these and uses these or finds his own ways to get what he wants.

Appendix 27

Examples of Thematic Map in Progress (paper and electronic maps for Frustrated group from Findings Chapter 3)