Addressing the Needs and Experiences of Disabled Children and Young People in Out-of-Home Care

Berni Kelly, Sandra Dowling and Karen Winter

Acknowledgements

Contents

1.0 Introduction

This report focuses on the third qualitative stage of a study examining the over-representation of disabled children and young people in out-of-home care in Northern Ireland (NI). The first stage of the study involved a review of regional policy and international research literature on disabled children in out-of-home care (Kelly et al., 2013; Dowling et al., 2013). This was followed by a survey of social workers which profiled the population of disabled children and young people in out-of-home care in NI (Kelly et al., 2015). This survey data provided a sampling frame from which 15 disabled children living in out-of-home care on a full-time basis were purposively selected for this final case study stage of the study.

This report begins with an overview of the findings from earlier phases of the study and an outline of the case study methodology including recruitment, consent and data collection processes. Findings of the case study interviews are then presented across the domains of pre-care experience, placement experience, birth family contact, social work support and access to specialist services. The identities of the disabled children and young people are also explored, including their everyday lives and experience of participation in decisions affecting their lives. Finally, issues relating to unmet need and examples of good practice are addressed. Throughout the report, anonymised quotations from disabled children and young people and their birth parents, carers and social workers will be integrated to illustrate the key themes. In addition, some of the pictures disabled children drew as part of their interviews are also included, with identifying features removed in order to maintain confidentiality. The report concludes with an overall discussion identifying the core themes from this phase of the study and recommendations for the future development of policy and practice relevant to the lives of disabled children and young people in out-of-home care.

Overview of Findings from Earlier Phases of the Study

The policy review identified the following overarching themes consistently evident across the range of policy documents available: equality and rights; a whole child perspective; family-centred practice; participation; early intervention; person-centred care; and multi-agency practice. However, the invisibility of disabled looked after children (LAC)[1] in policy and strategy documents is notable as they are subsumed within the policy relating to both disabled people and children. Given the multiplicity and complexity of challenges facing these disabled children, and their poorer outcomes, greater attention should be given to this distinct group requiring targeted services to meet their specific and diverse needs.

---

[1] In NI, children who live in out-of-home care on a full-time basis are often referred to as 'looked after children' (LAC), reflecting the language of the Children (NI) Order 1995. These children can live in a range of out-of-home care including foster families, kinship placements, residential children's homes or specialist care settings.

The review of literature highlighted difficulties in establishing the prevalence of disability in the looked after child population due to a lack of clearly agreed definitions of disability across jurisdictions. From the available literature, it is clear that more disabled boys than girls are placed in care, and that they tend to enter care at an older age than their non-disabled peers. In terms of impairment type, those with intellectual disabilities and mental health needs form a greater proportion of the population than other types of impairment. Previous research shows that disabled children enter out-of-home care for many of the same range of reasons as their non-disabled peers but are at greater risk of neglect, abuse and violence than non-disabled children. It is also noted that disabled children are more likely to be voluntarily accommodated in care than subject to a court order, which may reflect inadequacies in services aimed at supporting parents of disabled children to continue to care for their disabled child at home. Two key gaps in available research were highlighted: studies examining outcomes for disabled children in out-of-home care; and participatory studies incorporating the voice of disabled children or young people living in out-of-home care.

Following these reviews of policy and literature, the study progressed to a survey of social workers which profiled the population of disabled children and young people in out-of-home care in NI (Kelly et al., 2015). This included 323 fully looked after disabled children and young people who were living in out-of-home care on a full-time basis, usually in foster, residential or specialist care settings; and 164 disabled children and young people who were looked after solely due to short break stays exceeding 35 days in one year or more than 28 consecutive days in one year. The total of 323 fully looked after disabled children and young people represents 11.2% of the total looked after population in the same period, confirming their over-representation in the care system, as census data reports 7% of the general child population are disabled (NISRA, 2011).

Those who are fully looked after often come into care due to child protection concerns. In contrast, short break groups are looked after for family support reasons (although there are safeguarding issues for some). Unsurprisingly, then there are a number of notable differences in the findings for the two groups. For example, in the fully looked after group, the two dominant impairment types were intellectual disability and mental health, followed by those with multiple impairments. In contrast, almost all of the short break group had an intellectual disability, with many reported to have additional health needs and challenging behaviours.

In both the short break and fully looked after groups, males were more highly represented than females, however, this differential was more pronounced in the short break sample where males outnumbered females by 2:1. Gender proportions in both samples are in contrast to the general LAC population where there are only slightly more males than females (HSCB, 2013). In the fully looked after group, the numbers increase with age with the highest number being in the 16+ age group. This age profile also contrasts to the general LAC population and short break group where numbers decrease in the 16+ age group.

The fully looked after group were most commonly placed in foster care, however, they were less likely to be living in kinship foster care or placed at home than the general LAC population. By contrast, short break LAC mostly stayed in residential short break settings, indicating a lack of specialist family-based short break care. Placement instability was more marked for the fully looked after group who were also more likely to experience school change and vulnerability to risk-taking behaviours and criminal activity, particularly those with mental health needs. Proportionally, more of the fully looked after group had siblings who were also looked after and parents with disabilities.

In comparison with short break group, fully looked after disabled children and young people were reported to have less contact with professionals offering a range of support services. Across both groups, lack of access to specialist mental health services, particularly for those with co-existing intellectual disabilities and mental health needs who often relied on learning disability services to meet child/adolescent mental health needs. Lack of access to transition supports was also evident across both groups, despite the high numbers in the older age range.

The key messages from the policy and literature review and the findings of the profiling stage of the study provided the context for the final qualitative phase of study which involved case studies of a purposively selected sample of fully looked after disabled children and young people which are the main focus of this report. The findings of these case studies provide new insights into the care experiences of disabled children and young people and the perspectives of their birth parents, carers and social workers, which have particular relevance to practitioners, service planners and commissioners, and policy makers.

2.0 Methodology

The survey phase of the study profiled the numbers and characteristics of disabled children and young people in out-of-home care, therefore, this qualitative aspect of the study used a case study design to focus on their care experiences and the perspectives of disabled children and young people and other key stakeholders.

The objectives of the case study phase of the study were to:

- Explore perspectives on the factors that lead to disabled children and young people becoming fully looked after

- Examine the organisational arrangements and procedures within Trusts impacting on services for disabled children and young people in out-of-home care

- Investigate the experiences of disabled children and young people living in out-of-home care, including placement stability, services accessed and extent of family contact.

- Examine how the particular needs of disabled children and young people are met, or could be met, within public care and in a multi-agency context.

- Identify any examples of best practice in meeting the needs of disabled children and young people in out-of-home care.

The case studies were constructed in two stages. The first involved a close reading of the child's social work case files with key information about the child and their pathway through care recorded on a case file pro forma. The second stage then involved semi-structured interviews with children and young people as key participants in each case study in addition to the important adults in their lives: birth parents and carers/residential key workers (where possible and relevant), and social workers. Finally, senior managers with responsibility for children's disability and LAC services were interviewed to further explore the relevant policy and practice issues. Approval from each Trust's research governance team and ORECNI was secured prior to the commencement of data collection.

2.1 Sampling

The study originally aimed to identify 20 disabled children and young people to take part in the case studies, however, due to complex consent processes (outlined in more detail below) and time required to recruit, this number was reduced to 15 case studies. These participants were selected from the sampling frame developed as part of the earlier stage of the project which profiled the population of disabled looked after children in NI (Kelly et al., 2015). A purposive sampling process was used to ensure the 15 disabled children and young people represented a range of characteristics and care experiences:

1. Impairment type
2. Gender
3. Age (across two age ranges: 4-11 and 12-16)
4. Reason for being in care
5. Number and types of placements

We were also able to include children who had been in care for longer and shorter periods of time and who had siblings who were also in care (in the same placement or not) or who had remained with birth parents. Table 1 below provides a summary of the characteristics of sample of children and young people. In addition, further details for each child and young person who participated in the case studies are provided in short pen pictures in Appendix one.

CHARACTERISTICS OF SAMPLE OF CHILDREN AND YOUNG PEOPLE	
Gender	6 female and 9 male
Age	6 aged 4-11 years; 9 aged 12-16 years
Impairment	6 single impairment type : ID(4), ASD (1), MH (1) 9 co-existing impairments ID+PD (3), ID+ASD(3), ASD+MH (3)
Placement type	Non-relative foster care (6) Kinship care (3) At home on Care Order (3) Residential Children's Home (1) Mental Health Unit (1) Residential Specialist Community (1)
Time in care	<6mths (1); 1-2 yrs (3); 3-5 yrs (4); >5 yrs (7)
Reasons for entry to care	Neglect (9), Parents not coping (5), beyond parental control (2), Physical abuse (4), Emotional abuse (3), Potential Sexual abuse (2), Witnessing domestic violence (3), Child detained (1)
Siblings	Siblings looked after in different placement(5) Siblings looked after and in same placement (2) No siblings (3) Siblings not looked after (5)

Table 1: Characteristics of sample of children and young people

2.2 Negotiating Access

Each child's named field social worker was contacted to determine whether a child could potentially be included in the study. It was important to first ascertain whether there were any circumstances which could mean that a child could be adversely affected by participating in the study. Social workers were well placed to make this assessment and, indeed, in 43 cases, consent processes were not pursued because birth parents sharing parental responsibility had disengaged/were not contactable or because the social worker decided the child or young person should not be approached to take part due to concerns for their wellbeing. A number of reasons were provided, giving a sense of the complexity of challenges and difficulties in these children's lives including:

- Potential harm by revisiting trauma or complex family issues;
- Difficult current circumstances e.g. transitioning between placements or recent bereavement;
- Deteriorating child or family illness e.g. degenerative condition/mental health or hospitalisation;
- High level anxiety/conflict related to current court processes; and
- Current crisis in care placement.

Given the complexity of this process, it took considerable time to make contact with social workers, and allow time for information to be shared and considered by all of the key stakeholders. In addition, there were some cases where children or young

people were undergoing a significant change in their lives and needed more time before social workers could approach them regarding the study. For example, moving to a new care placement, returning home to their birth parent or experiencing a period of illness. For all of these reasons, usual recruitment processes took longer than originally expected. This delay was further affected by the high numbers of cases where consent processes could not be progressed by those holding parental responsibility (for the reasons outlined above) and, therefore, cases had to be re-sampled using the profile sampling frame.

2.3 Recruitment and Consent

In instances where children were thought to be potential participants, social workers were asked to share information about the project with whoever held parental responsibility for the child and ask for consent to the child's participation, as well as consent to their own participation. Birth parents were the key people holding parental responsibility, often shared with the field social worker. Therefore, parental consent was required in most cases, particularly when parents were in regular contact with the child or routinely involved in exercising parental responsibility for the child. Where parental responsibility was shared with the Trust, the child's social worker also gave consent to their participation. If the birth parent did not exercise parental responsibility or was out of contact with the child/Trust for a period of six months or more, field social worker consent was suffice. This was the process agreed at the stage of ethical approval to ensure respect for dual parental responsibility.

In seven cases birth parents refused consent. When reasons were given, refusals were mainly due to family illness or ongoing issues related to the child's admission to care including, pending court hearings.

When we had achieved consent from the individuals holding parental responsibility, we were then in a position to approach the child themselves to ask whether they would assent to participation. Two children decided not to participate. One child refused because they did not see themselves as being looked after and the other refused because they did not identify with being a disabled young person. In the latter case, efforts were made to explain the diversity of children and young people involved in the study via the social worker but the child still did not consent. Once the child agreed to take part, we then asked for consent from the child's main carer (foster / kinship carer) and the child's field social worker to their own interviews as part of the case study.

2.4 Accessible Information

We produced a range of sources of information for potential participants. Separate information leaflets were prepared for social workers, carers and parents. An easy read and more comprehensive version of the information leaflet for parents was also

prepared and we took advice from social workers who knew the parent(s) as to which leaflet was the most appropriate to use. For children and young people, information was prepared in a range of formats. Accessible leaflets which included images and text were made available. In addition, we worked with Barnardo's Sixth Sense group to produce a DVD which shared information about the study. This became a discrete project within the wider study as we worked with young disabled people in the group to prepare a script, perform roles in the DVD and then work together on editing and production. The DVD was well received by young people who were interested in taking part and we received feedback that, in most instances, it encouraged participation.

2.5 Case File Reading

Following recruitment to the study, the first task of the researcher was to read the child's social work case file. A pro forma was devised to guide case file reading (see Appendix 2) and facilitate the collection of data under key areas of interest. This focused on information about impairment, education, becoming looked after, placement experience and change, reason for becoming looked after, court processes and legal status, and use of services.

Files were detailed and extensive and the number of files depended on the age of the child, the length of time looked after, the complexity of the case and the social work team holding the case. For some children up to five files were available, however, for others there were many more. When children had been transferred between LAC and disability teams at different stages of their care journey, more files were likely to be available. When children had transferred to the 16+ team it was not always the case that the files from their younger years were held by that team and, in these cases, fewer files were available.

Case files were read in social work offices. A quiet place was designated within the office for case file reading and teams were very accommodating in providing a space for the work to be completed. In some instances, repeat visits to team offices were needed to ensure that file reading was complete as this was a time intensive process often taking two to three full days to complete.

Case files provided rich contextual information on the child's life before coming into care and during their time as a looked after child. The complexity of life as a looked after child in terms of the review structure, statutory visits and the number of professionals present in children's lives was clearly evident from the files. The extent of detailed reporting on behalf of social workers was also apparent.

2.6 Case Study Interviews

A series of semi-structured interviews were arranged on completion of case file reading. Interviews took place at a range of locations. Children were met in their home environments and their main carer was also interviewed in the home. Birth parents were also interviewed in their own homes. Social workers were then interviewed, usually at their place of work. This was to encourage impartiality on behalf of the researcher when interviewing children and parents/carers, only having prior information from the case file. Finally, interviews were conducted with senior managers of children's disability services and LAC services in each of the Trusts. These were either carried out in person or by telephone depending on what was feasible. The breakdown of the total number of interviews with each respondent type is outlined in the table below.

RESPONDENT	NO. OF INTERVIEWS
Children/young people	15
Birth parents (4 fathers, 9 mothers)	13
Foster parents (3 kinship, 6 non-relative)	9
Residential key worker	2
Social worker (1 social worker held 2 cases)	14
Assistant Director/Senior Manager	10
TOTAL NO. OF INTERVIEWS	**63**

Table 2: Total number of interview respondents

All interviews were semi-structured, allowing the researcher to ask questions about core themes related to the case and questions about broader practice issues. Respondents also had the opportunity to introduce new themes or issues that reflected their own experiences. The topic guides for all interviews with each respondent type are provided in Appendix 3. All interviews were audio recorded with prior consent and transcribed for analysis.

Interviews with children require particular mention. Children who took part in interviews ranged in communication abilities depending on age and impairment effects. Their interviews were also semi-structured but utilised a range of tools to assist with communication and to facilitate their engagement with the researchers. These included: an 'All about me' book; 'feelings faces' illustrating a range of emotions; symbol cards for yes/no and thumbs up/down; and blank paper and colouring pens. Younger children and those with more limited verbal communication skills or more severe levels of impairment were more likely to engage in play and activity-based exercises based on the 'All About Me' book. This activity-based book covered the main interview topics but used pictures and key words to engage in a more accessible way with the child. Children were encouraged to use the book to express their thoughts and ideas and were also given the opportunity to write or draw in the book. Several children used this to great effect, their drawings providing additional detail and insight to any verbal responses. The conversation which took place as the book was being completed was audio recorded and formed part of the

interview data collected. Older participants and those with less severe impairments preferred talking and writing, similar to a conventional interview.

'Feelings faces' were used by both younger and older children to articulate their thoughts and emotions in relation to issues raised. These were simple picture cards which showed images depicting a happy face, a sad face, confused, shocked, angry and so on. Children could also draw their own feelings faces on blank face cards. We also used a traffic sign styled STOP sign which children could use should they wish to end the interview at any time. These approaches have also been utilised effectively in previous research with disabled children and young people (Kelly, 2007; McNeilly et al., 2015).

Most of the children and young people who took part in the study easily engaged in the interview process. In fact, in some instances the researcher found children more able to take part in the interview than their social worker had suggested, with children showing considerable levels of self-reflection and insight. Only two children found it challenging to take part in the interview process. One of these children was very young and had severe learning disabilities and complex health needs. For this child, observations were conducted over three visits. The second child tried to engage with the interview but was unable to maintain concentration. This child had complex needs and presented with challenging behaviours. Observations were also made with this child over two visits. The researcher spent time interacting with these child through touch and play; and also observed the children's interaction with their carers. The research team found it was important to use alternative ways to facilitate the participation of these children in the research and to incorporate their perspectives.

2.7 Analysis

All transcribed data was uploaded into MAX-QDA, a qualitative data analysis software package that facilitates the systematic coding and recoding of interview data as themes emerge during the analysis process (Kus Saillard, 2011). In order to ensure validity, one transcript was coded thematically by the two main researchers and the codes developed were then compared to check whether or not similar themes were identified independently. Based on this interpretive validation process, a coding framework was then developed and applied to the remaining transcripts with any additional themes drawn from the data added to the framework. This iterative technique of dual inductive coding facilitated a rigorous approach to the analysis process (Robson, 2011).

3.0 FINDINGS

The findings of the case studies are presented following the sequence of children's experiences from pre-care and admission to care through to placement experience and leaving care. Access to a range of services is also considered, including the role of social workers in the lives of disabled children and young people in care. In addition, core themes emerging from the data in relation to children's experiences are incorporated including permanency, identities and transitions. Throughout the report, the views and experiences of children and young people are prioritised with data from interviews with parents/carers and social workers integrated to provide a holistic picture of the findings relevant to each section.

3.1 Pre-care and Coming into Care

Children and young people who took part in the case studies had a variety of pre-care experiences and pathways into care. Some were looked after from a very young age and had spent most of their lives in care, others became looked after later in their mid childhood or teenage years. Some of the children had experienced relative stability in their placements, whilst others care stories were characterised by multiple placement moves and instability. The reasons for becoming a looked after child also varied and for some the impact of impairment effects on the parenting role had a bearing on the reasons for their entry to care and placement options. Children had varying levels and forms of contact with their birth families, but common to all was the ongoing importance of their birth families in their lives, even when contact with birth families presented persistent challenges.

3.1.1 Reasons for Entry to Care: Abuse, Neglect and Relinquishment

A number of reasons for entry into care were reported for children in the case study sample and, in many cases, there were multiple reasons for admission to care. Neglect featured commonly, being cited for 10 of the 15 cases, and often in combination with parents not coping. For six children, specific experiences or risks of abuse also featured in their pre-care story, including emotional, physical and/or sexual abuse.

Several children were voluntarily placed in care often due to a breakdown in the birth parents capacity to continue with the parenting role in the context of multiple impairment-related needs and/or challenging behaviours. For these disabled children, their level of need impacted on their birth parent's caring capacity and their entry into care. In one case, the child's mother was unable to meet the physical demands of caring for her disabled child due to her own health needs, although her non-disabled children remained at home with her. In another case, the child was placed in care as his challenging behaviour became too difficult to manage in the home environment, placing other family members at risk. In this case, the young

person was detained in a mental health unit due to risks to themselves and others. However, the family remained very closely involved in the child's care and had regular family contact.

The majority of children and young people in the case study sample had been engaged with child protection services prior to entry to care, with 11 of the 15 being placed, at some point, on the child protection register. Most of these young people were de-registered once subject to LAC procedures. Two young people were not subject to child protection procedures as they were voluntarily placed in care and there were no child protection concerns. Two other young people were subject to child protection investigations but not placed on the register as they were taken into care.

During interviews with parents there was much reflection on the reasons for their child's entry to care, with each story being individual. One parent who had an intellectual disability, talked of her fear at being responsible for her premature baby and, as a result, her child initially lived with her parents and then in non-relative foster care. Another mother described her realisation of the situation she had been in prior to her children being taken into care:

> *'It was due to my... going off the rails; just having house parties and you know getting myself involved with the wrong crowd... taking drugs. Turns out I had an addiction so just realising that. I didn't want to accept any help. I thought I was a good mum, but obviously I did need help and that's when everything hit rock bottom'* (Birth mother).

One parent described how her child was taken into care following violent episodes in the family home. This mother, however, also highlighted a key underlying reason for her child's level of aggression was her undiagnosed ASD (later diagnosed during her time in care). This parent described how she had unsuccessfully sought help in relation to her child's presentation and behaviour for many years. She felt she knew something was *'wrong'* but that no one would listen to her. This parent felt that her child's admission to care had been due to a failure to understand her presenting needs and behaviours and a lack of early intervention and partnership working:

> *'I fully understand child safety is paramount.... but I think in our case, they went in like a sledgehammer and a sledgehammer wasn't needed. I really feel that if they'd gave me support… if they had of listened to me when I was saying she was on the autism spectrum... rather than bang, you're a bad mother'* (Birth mother).

Two further parents highlighted the risk posed by their child in relation to their violent behaviour within the home, which led to admission to care due to being beyond parental control:

> *'Just his violence had got that bad... lashing out and throwing stuff, wrecking his room and... everything in the room would have come down the stairs, drawers, TV, toys the lot... you were just sort of walking on egg shells round*

him... I would have tried to always take the beatings... it was a case of I just can't cope anymore... I think for my own mental health as well you knew something needed to be done' (Birth mother).

Parents also reflected on their memories of their child being placed in care. In some instances, concerns expressed mirrored those of social services and, on other occasions, birth parents perspectives contradicted their social worker's views. One father recalls witnessing the neglect of his children during contact visits when the children were initially living with their mother:

'At the start I don't think they were doing their job. They had more interest in [mother] than in me. They believed her more than they would believe me… I seen it coming… every week I went up to see the wee ones... she couldn't afford to buy milk... and you would have smelt them... I [had] to take them in and get them washed' (Birth father).

Others disputed the reasons for their child going into care describing a misinterpretation of circumstances on behalf of social services. One father denied suspicions of having sexually abused his child although he admitted having physically hurt his child which resulted in her admission to care. Another parent had agreed to a short break placement for her children because she was unwell, however, her children never returned to her care again:

'I put them in respite and didn't get them back. I wasn't well, it wasn't that I was not coping, I was.... but I started to believe things that weren't true and I felt like I was starting to lose it. I should have got them back' (Birth mother).

Foster carers also referred to the reasons why children came into their care. As neglect was frequently reported as a reason for children becoming looked after, this was reflected in the recollections from carers, as one kinship carer explained:

'He was coming here dirty and with chest infections and he hadn't been changed… it just gradually got down and down and down... and then I took them in' (Kinship foster carer).

Problems with substance abuse were also reported by carers as a reason for children becoming looked after. Others reported physical abuse and non-accidental injury that had precipitated placement of the child in care.

Similarly, social workers identified a complex and interrelated set of factors that could lead to the admission of a disabled child into care. These included: parental factors (including poor adjustment or limited personal, economic and social resources); child factors (including high level needs and challenging behaviours) and child abuse or neglect. No one factor appears to dominate but rather there are multifarious factors often reflecting the same reasons that lead to non-disabled children's entry into care.

Social workers considered neglect and abuse that could lead any child into the child protection and care system, including disabled children:

> 'It was a total necessity that she came into care. She was really badly neglected, totally neglected. None of her needs were met at all. It was horrendous … There was a lot of severe domestic violence' (Social worker).

This is further illustrated in the interview excerpt below where the social worker concurs that disabled children come into care for many of the same reasons as non-disabled children:

> 'In my experience it has been child protection... concerns in the care delivered at home… it's been exactly the same as other children the reasons why they've come in to be looked after. Parents for whatever reason... not managing and not prioritising their children and leaving them in vulnerable situations' (Social worker).

Parental Capacity and Stress

Whilst acknowledgement that disabled children enter the care system for many of the same reasons as non-disabled children, it was also clear that additional factors could be underlying in child protection issues for disabled children. One senior manager explained the various reasons why disabled child may come into care:

> 'We've got two sets of issues, a smaller number who wouldn't be good parents anyway... people that have maybe been through the care system or have mental health problems or addiction problems... [for most] it is a combination of parental breakdown and neglect, families saying to us we cannot cope, not only can we not cope, I may harm this child if you don't do something soon, and what we tend to do is the scaffolding approach... all the family support stuff... most of it is the burn out and falling apart... quite literally almost leaving the child on the doorstep... the actual harm doesn't happen but the whole thing breaks down, however sometimes in the disabled children's world neglect can be masked a bit and we tend to think it's all about the poor carers...' (Senior manager).

Indeed, the interpretation of thresholds of risk of significant harm for disabled children can be challenging when disabled parents are under immense strain in their caring role:

> 'There is a view that most of the child protection issues that arise with disabled children are more linked to the stresses and the challenges of dealing with a child's disability... there's less a sense of parents who just cannot parent their child... do we have a higher threshold? Is it more of an excuse for them than it is for another parent who loses the rag and lashes out at their child? Is this a child abuse, child protection issue or is this an

absolutely stressed and exhausted parent? I think there's maybe a higher tolerance... if the child is on the register there will be a whole package of support linked at reducing that stress and avoiding that child becoming looked after and maintaining them within their own home and I suppose it begs the question then should that be part of the earlier family support package and planning? It's a question of early intervention' (Senior manager).

Challenges were reported in relation to implementing the child protection procedures in respect of disabled children in a context where there is an emphasis on keeping families together often through high levels of support services and where the focus on impairment can potentially supersede emergent child protection concerns. This highlights a concern that there could be occasions when an over-emphasis on supported stressed parents occurs at the expense of early detection and decisive responses to concerns about abuse and neglect to ensure that a child becomes 'looked after' if appropriate and necessary to protect their welfare. Interestingly, some social workers also highlighted the challenges they had encountered in court when seeking a Care Order for disabled children, with indications that the judiciary had an over-emphasis on maintaining disabled children in the birth family home despite clear child protection concerns. As one senior manager explained:

'It can be very difficult to get a Care Order... depending on which judge you get... taking it from the perspective that the parent is under so much pressure and the Trust isn't stepping up to the plate in terms of what services it should be providing to keep things going... or worse the increasing trend is ok I'll make a Care Order at home so you've got all the responsibility but there's nothing you can do... and we're getting that day in day out, children are being left at home who maybe shouldn't be there, the court copping out basically and saying well we'll grant a Care Order but still back to you... and it's never going to be stable enough' (Senior manager).

Social workers noted that some parents did not adjust well to the having a disabled child in their family which impacted negatively on attachment, bonding and parenting capacity. In contrast, there were other cases where parents had developed close bonds with their child but were unable to provide the structured care they required due to their complex and multiple needs. Earlier intervention was emphasised to assist parents and to prevent escalation of low level needs as children grew older, as the extract below explains:

'We have one child whose parents absolutely adore him... and are so protective of him but they cannot... behave in a structured way because they always have to indulge him... and it's far too late for them because he's a teenager now... maybe when he was 2 or 3 or even younger if we had been able to intervene and kind of put some structure around them... at the root of their situation is an immense loss that they've never been able to come to terms with...' (Senior manager).

Other social workers highlighted that sometimes parental misunderstanding of their disabled child's needs and reluctance to take on board advice could have a negative impact and contribute to the reasons for a disabled children coming into care:

> *'A lot of parents don't fully understand their child's disability or how to work with it. Their resilience goes quicker cos the things they are trying to use are never going to work with that child.... they're not doing what a behaviour specialist may have advised... sp kids can become very behaviourally difficult and… we would have a lot of families who get to the point of saying can you just take my child for a while'* (Social worker).

As noted above there are families who adjust well but who become worn down trying over time to meet the ongoing needs of their disabled child. This theme arose in a number of the interviews as indicated by the following quote from a social worker:

> *'The stressors for families is if you have a child who has challenging behaviours, if you have a child who isn't sleeping at night... and maybe a child who isn't relating to you... that's completely wearing for a family and … it just got to the stage where the mummy was saying 'I can't do this, I can't'. And I would challenge anybody who could have done it'* (Social worker).

Furthermore, parents whose personal, economic and social resources were limited and who had other children to care for sometimes struggled more. Social workers gave detailed examples of the financial challenges for parents of disabled children, including financial struggles for middle class families:

> *'I call it the middle poor… those families where maybe there's one bread winner or somebody's had to stay at home to look after the disabled child so there's only one income but it used to be two. They are the people who are getting nothing absolutely nothing… and won't ask and feel you know, no, no, no, no somebody else needs it more than me'* (Social worker).

Social workers also reflected that caring for a disabled child can lead to social isolation which impacts on parental wellbeing, thereby, reducing capacity to cope. Sometimes a parent of a disabled child who is not coping can feel unable to turn to other family members for help due to their child's high level of need or the health/age of family members. Social workers can also find it difficult to mobilise support from the extended family:

> *'Less and less I think we have that extended family situation... it's not the way maybe thirty years ago where you had a grandparent who was maybe there on board... it's much more difficult... I've never used it and I think that's indicative of how things are'* (Social worker).

In the context of limited social resources, parenting can be under intolerable pressure and become compromised, leading to the heightened vulnerability of disabled children to abuse, neglect or relinquishment into care.

Some social workers also indicated that disabled children had come into care because of the impact of their parents' mental, cognitive and/or physical health difficulties or abusive relationships. Social workers indicated a potential link between parental ill health and the impact of their caring role over time, highlighted in the following interview excerpt:

> *'Mum's mental health for a period of time was very low and that would be a big thing for a lot of our carers... the longer you're caring the more... your mental health and resilience goes down'* (Social worker).

A key aspect of parental capacity is the extent of their disabled child's complex and often challenging needs. Disabled children often presented with co-existing cognitive, physical, sensory, mental or other impairments and could require high levels of supervision, structure and intimate personal care. In this context, some disabled children with multiple and complex needs became looked after when they reached adolescence and their parents could no longer cope with their challenging behaviours and high level risks at home. One senior manager reflected on the routes to full-time care for these young people:

> *'Serious conduct disorder, challenging behaviour, autism, co-morbid mental health, learning disability, autism and attachment disorder, that's not uncommon, those kids go in via the treatment route, get stuck there for a really long time... in a hospital ward or specialist residential... families just say 'can't do it... because the resources aren't there in the community, so you've got family burn out... families almost saying please take the child into care so they're voluntarily asking'* (Senior manager).

Social workers also reflected on the multiple needs of a disabled child and the challenges in co-ordinating the multiplicity of services and professionals involved in their lives. In this context, social workers emphasised the importance of early intervention and support for parents of disabled children to prevent family breakdown and admission to care, as the following extract illustrates:

> *'You would like to get in early and try and put in services early and that's... why early intervention is so important... that feeling of not being alone... if you put in a small amount early on then people will cope. If you wait to crisis, then everybody is in crisis and it's too late'* (Social worker).

This is further illustrated by comments from senior managers below:

> *'I see it escalating where parents have either not wished to have support early enough... or have had difficulty accessing it or and getting to exhaustion very quickly and sometimes under everybody's radar... that is one of the areas that we have to try and get better at... early identification'* (Senior manager).

Such early intervention was critical for disabled children deemed to be on the edge of care:

'We have some very much on the edge of care and it's a cocktail of support that we are putting together be it direct payments some residential short break provision... community outreach... and family support workers because... if families on the edge are referred to the professional teams when they have got to a point where they are exhausted professionals are coming up with care and behavioural support plans... but there is no way these parents can start to implement them... they are exhausted so we need to implement it within the home incrementally... give support that's over and above... and you can see tremendous benefits for that and that is usually short sharp intervention... those are the programmes that do prevent family breakdown' (Senior manager).*

'Do I think that additional interventions at a point in time to a range of families would have prevented admissions to care? The answer would be yes... what we've got to get more good at is diagnosing what type of support that people need and the time they need it and what are the consequences of us not providing that support and sometimes that will be admissions to care' (Senior manager).

Other senior managers concurred with this viewpoint but were concerned about how well families could be supported in the context of austerity measures and service reduction, particularly those caring for children with complex health care needs:

'The resources that we have are much more limited than we would like to have. We are struggling to put structures around some families, the biggest issues for us are families who are imploding because of the burden, you know the emotional weight that they're carrying and sometimes the practical difficulties... the capacity within the system to provide really responsive support, emotional support to those families is not there... so some are using the term edge of care to describe those kind of children who have extremely complex needs and who are teetering on a looked after situation... so the issues for us are actually resources... the financial situation is almost impossible' (Senior manager).

3.1.2 Legal Status

Five children looked after on a Care Order either entered care with this legal status or entered care under an Emergency Protection Order or Interim Care Order. The remaining 10 children in the sample were voluntarily accommodated. Of these five eventually moved from a voluntary legal status to a full Care Order. A Care Order was being sought at the time of the study for a sixth child whilst one other was detained under mental health legislation following voluntary admission to care. Three children's legal status remained voluntarily accommodated at the time of the study.

There was a lack of clarity in some kinship carers' understanding of the legal status of the child in their care as they were uncertain about how the child's status impacted on their parental responsibilities to the child. One birth mother also expressed confusion as to the decisions she needed to make in relation to her son's care, indicating that she was not always being listened to and there was little opportunity to revisit decisions made:

> *'It's come to a stage now like where I've to make a decision about him... I have very little family support here and I've got to make the right decision for him... it is hard for me... I'd like shared care now... and I want to be listened to on that... they want to hear me saying that I want him in long term foster care... I want to be given a chance as well... Eventually then they might have to get a court order against me to just to keep his placement. I don't know sometimes it can get very confusing as well, the legal aspect of it'* (Birth mother).

Similarly, another parent had become uncertain about her role in her child's life in terms of parental rights and asked the researcher for clarification:

> *'Sometimes I think you know social services have a right over her... am I still the mother that makes the decisions? Sometimes I'd still be pretty confused about that'* (Birth mother).

Another mother, however, was clear about the legal status of her children and described having the support of social services whilst she worked towards getting the Care Order on her children discharged.

The legal status of children could impact on the roles and responsibilities of birth parents, and the extent to which they were involved in decisions affecting their child's life. Some parents felt that they were routinely included in decisions, as one parent stated:

> *'For hospital appointments and all the social worker phones me... like when he fell in school they phoned the foster carer and me... So I get informed all the way'* (Birth mother).

By contrast, some parents talked about how things had changed as time had passed and they increasingly felt left out of decisions about their child's life, as one parent stated:

> *'It was really, really good but it's starting to seem like they're forgetting that they're my kids... and it's getting really annoying'* (Birth mother).

Voluntary Accommodation

Some social workers highlighted difficulties related to looking after children who were voluntarily accommodated rather than being under a court order as they could

theoretically leave care at any time. One young people voluntarily accommodated in residential care highlighted that her legal status meant she could leave the care setting at any time. Her social worker commented on some of the tensions this could raise:

> *'There's never been an Order on her so I suppose that's been difficult too because she then doesn't always accept what staff are advising her because that's a war cry "You don't have any… my mum has to say" and then it puts her mum in a position where she has to be honest… her mum does well to be very strong with her and say, no, you know you can't come back here'* (Social worker).

However, in this case, one benefit of being voluntarily accommodated was the ongoing close involvement of the young person's mother during her time in care. Her social worker commented on the crucial support her mother provided, including lengthy contacts outside the home, assisting residential staff regarding her behaviour or needs, and spending time in the home helping her to settle.

Short Break LAC

Social workers and senior managers also consistently expressed concerns about the current legislative requirement to classify children using short breaks for more than 24 hours in one stay as looked after children, subject to LAC procedures. This issue caused much concern for parents who were mostly using short breaks as a preventive service for family support reasons rather than as a child protection service for children at risk of neglect of abuse. The following quotes are selected to demonstrate this point from a range of data collected on this subject across interviews with professionals:

> *'Ridiculous... just completely over the top for what we're doing. And you think of the amount of professional time then that you are allocating to that as well... for a child who's maybe having twenty nights a year... everybody recognises it needs changed'* (Social worker).

> *'Parents would be unhappy with the forms and the process... we usually begin LAC reviews by apologising for the forms and explaining why we have to use inappropriate forms... not fit for purpose... some are very offended by them and find them fairly disabling... our team leaders would say they're extremely burdensome on staff as well'* (Senior manager).

However, some social workers expressed the opinion that the LAC review process, while it could be made less formal, can be useful because it ensures that all of the complex and ever changing information about a child's needs, who is responsible for them across the multi-disciplinary team and how and when they are to be met, is written down and held in a detailed care plan that is routinely reviewed, as the following quotes illustrate:

'It's useful because we're looking at all the aspects of the child's life so medically, health wise, their development, the school. How's things going at home? How's things going at the foster carers? Is there any issues that are impacting on that?... because all the time new things are coming to the fore… it is hard to get all the professionals round a table but when you do it can be a very useful process... and I think parents can see that that can be beneficial' (Social worker).

'Some parents have been very happy for that to be the case because they see that as being a means to get services, like if it's agreed at a LAC review then somebody is accountable at the next LAC review... and LAC reviews are very useful for understanding the whole life of that child... but I think it's a bit of a sledgehammer and nut job... there should be other creative ways of providing them with that support without having as draconian a measure as having to have their child of looked after' (Senior manager).

Overall, most professionals indicated that reviews of short breaks could be managed under family support arrangements rather than LAC procedures:

'It could be managed through family support. A lot of these children would not be coming into care only for the fact that the parents are exhausted and they genuinely do need a break... it's not that the child's met a threshold of harm or compromised parenting… there needs to be some way of managing this without having to take them into care' (Senior manager).

'We need to be very careful not to throw out babies and bath water so six monthly robust review is probably important because of the vulnerability of these children but the level at which it is chaired could certainly come down a level' (Senior manager).

Aside from LAC procedures, social workers also raised concerns relating to children making extensive use of short breaks and sometimes multiple short break services resulting in lengthy periods away from their birth families. Some of these children were deemed to be on the edge of care and for some there were ongoing concerns about their parents' capacity to continue caring for their disabled child.

'Procedurally if a group of children are ending up in short breaks longer than the 50 days then really they are shared care… so let's validate them as fully pledged shared care looked after arrangements if that's the case' (Senior manager).

In some cases, these children came to the attention of the inspection authority because they had breached the allowed length of stay in one period in a short break setting (commonly referred to as the '90-day rule'). However, social workers and senior managers reported a sense of frustration with inflexible regulations which prohibited longer stays in residential short break placements and highlighted the need for such a high level of support in some cases:

'We were threatened with the failure to comply with RQIA... inappropriately use your short breaks unit and breach... but that doesn't bother me either because the child's needs are the most important thing' (Senior manager).

'For some of the families that we work with... we can come up to 90 days quite quickly... that's simply because we're trying to keep the family together and because the parent or the child needs respite... I think 90 days is quite low... and families are left without that support that they maybe find the most beneficial' (Social worker).

As a result of such regulations, social workers tried creative ways to provide additional full-time care without breaching length of stay regulations, including use of holiday schemes.

Many social workers and senior managers expressed disappointment that recent indications that the policy on LAC procedures for short break users may change had not been realised:

'We had a moment of hope when the mood music seemed to be it was all going to change but I think the impetus seems to have gone... the change that is needed is not massive... but you would need children's legislation to change it all... my understanding more recently is that they have deferred that and that saddens me greatly so if there's any possibility of it getting back on it the agenda for reform I would welcome that' (Senior manager).

Political instability in NI was also a contributory factor to the lack of policy change on this issue, as one policy maker explained:

'The proposal is to move children who receive respite for the purpose of assisting their families to receive respite from Article 50 children in care to Article 18 family support role... but changes to the law have to be approved inside the mandate of the existing Stormont government which is also tagged on to more controversial issues in NI such as the gay adoption issue so unfortunately we have seen a lot of stalling... it's extremely frustrating' (Senior manager).

Some social workers and senior managers indicated that children availing of extensive and/or multiple short breaks may actually require a formal shared care arrangement:

'Anybody who is getting 90 days, there are usually big issues... the child's extremely challenging behaviour and... very often co-morbid autism, communication disorder, attachment disorder... and they will be predicatively the next children who need a residential place if we don't find other resources to keep families going...it's usually linked to home circumstances and parental capacity to continue to manage' (Senior manager).

'If a shared care arrangement is what a family can cope with and it works for the child i.e. they don't feel that they are being pushed out and from pillar to post and they can manage the arrangements that has to be better than a full time care arrangement... clearly those families can cope with them 2 or 3 nights a week... and some of those arrangements work really, really well... and sometimes naturally merge towards a full time return to home' (Senior manager).

3.1.3 Reflections on Coming into Care

Young people recalled some distant memories of their life before coming into care and others remembered their experience of coming into care, although these reflections were likely to be affected by the time delay and their care experience. For example, one young person reflected on how he wished things had turned out differently, feeling powerless to effect change:

'*Actually I would say that sometimes it felt really nice being away from home and some not nice... 'cos I really didn't want to be with my mum at the time... but now I do and I can't leave here 'cos the social workers think that it's a good place'* (Adam).

Another child drew a picture (see below) as he recalled feeling confused and 'a wee bit shocked' at leaving his birth mother's home and going to live with foster parents, where he still resides:
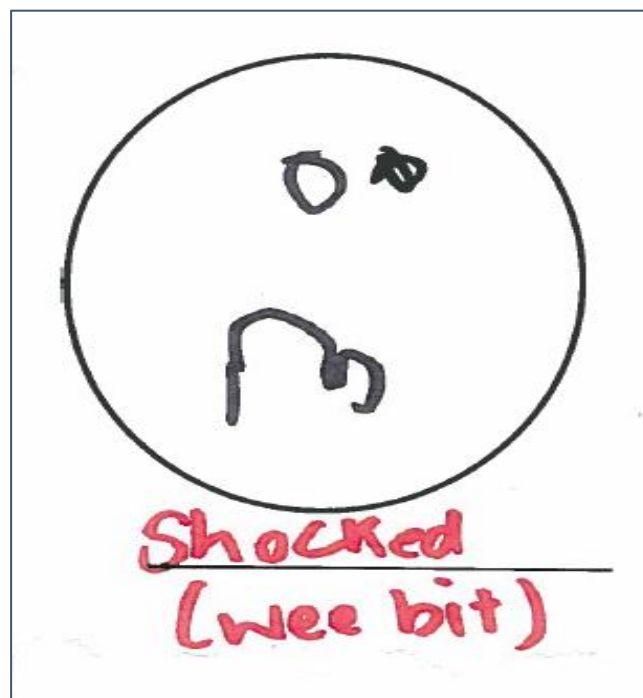
Foster carers also reflected on receiving children into their care. For some, the process was described as fairly smooth, in particular for kinship carers who had an existing relationship with the child:

> '…the social worker rang me up and she says could I take him?... he settled in no problem cause he was always up here anyway. Like I wasn't a complete stranger, no he just run about and played about' (Kinship carer).

Non-relative foster carers had less background information than kinship carers, however, some commented that they had been given a good deal of information about the child:

> 'About 90% of it yeah. His mum moved away... We know he have been sort of shifted from pillar to post because nobody could, for a better word, handle him' (Non-relative foster carer).

Others reported having less information than they would have liked when the child came into their care, particularly if the placement was tentative:

> 'To be honest we didn't get a lot of information, we didn't know the full extent of his needs... I think they were afraid we wouldn't maybe take him if we know the full extent.... They told us three weeks but that was just a sweetener to see how we got on... everything was just played down at that stage' (Non-relative foster carer).

Parents also talked about their memories of when their children were taken into care and their interaction with social services at the time. As explained earlier, some parents felt that social services had not listened to their views on the presenting issues and did not work in partnership with their family. One parent was unclear about the processes that led their child to becoming looked after, reporting that she did not understand the implications of the Care Order:

> 'I thought it's only scare tactics, cos I was in denial… then it was just very blunt on the phone… they put the Care Order out on my two children. I didn't believe it and I didn't even know what it meant. At that time again my head was gone, cloud nine… I just felt at that time that I could have been given better leeway or maybe it was just because I was in denial and I didn't know what was going on around me. Maybe they did give me more notice and I just hadn't really clicked on to it. I don't know' (Birth mother).

Another mother said that a social worker suggested her children go to a short break for the weekend to give her time to rest and cope with her upset emotional state. The mother agreed to this but her children never returned home from the short break stay. The following extract illustrates the depth of her feelings about her children becoming looked after:

> 'They made up so many lies... they just [messed] me about, they really did. Now there is just nothing' (Birth mother).

Other parents had agreed to their child's admission to care as they were deemed to be beyond parental control, with high levels of violence and challenging behaviours within the family home, as one parent explained;

> 'When he first did go into care it was very hard for him... we just could not handle it anymore... and it was hard on me with depression as well... and it was hard to let him go... very emotional... he was in a few places and some of them had seen what I had went through with him and had said you know wondered how I had stuck it for so long' (Birth mother).

3.2 Placement Type and Care Experience

Disabled children who were placed in care were either removed from home with the agreement of their parent or through a court order. Placement type varied across the case study sample. At the time of the study, six of the children lived in non-relative foster care and three in kinship care placements. Three of the children were at home on a Care Order, one lived in a residential children's home, one in a specialist hospital unit and one in a specialist residential community. Although four of the young people had experienced no placement changes and a further two had moved on only one occasion, the remainder had experienced more than one placement disruption with six young people having moved on four or more occasions, some as many as ten times.

3.2.1 Kinship Foster Care

Three children lived with kinship carers who were grandparents, aunts or uncles. These young people experienced stability in their placements and expressed a clear sense of being part of their birth family, commonly having routine informal contact with their extended families. Most reported having close and loving relationships with their kinship carers and talked of happy childhoods and good memories of these placements over the years:

> 'I was my granda's girl, in the summer I would go to work with him, and we would watch all cowboy movies together, we loved all the same things, I would just always be with him' (Shauna).

For young people a strong sense of connection and bond with family carers made it difficult to consider a future where they would not be in kinship care. One young person spoke of concerns at having to go to short breaks when his grandmother was unwell, and how difficult he found that separation:

> 'I was going to live with this person but I got real homesick. I was phoning the house demanding to come back here. I had to go there but I could not go away from someone I had known almost my whole life. I basically got really

homely here and could not live anywhere else… The plan was to stay there for two days full, and I could not do like twelve hours' (John).

Another young person felt very strongly that she always wanted to stay in a kinship care arrangement. This young person's loyalty to her kinship carer prevented her from disclosing her carers' substance misuse and her own mental health issues until a crisis incident resulted in a move to live with another family member. This young person's social worker reflected on the breakdown of her initial kinship placement:

'Her needs really weren't identified until the crisis incident. Up until that point nothing was offered cos we didn't realise there was a need… however, X [current carer] has been given support and it works well in terms of meeting her own mental health and emotional needs' (Social worker).

This young person secured a second kinship placement, however, she reported a sense of isolation when her carer was often out of the home due to employment and other demands. Her kinship carer reflected on how it had been difficult to adjust to the role and they had only recently developed an understanding of each other's expectations:

'We're trying to find some middle ground about time that we spend together… that's sort of been a bit difficult but I think we've got over the major hurdles... She knows what I expect of her and I sort of know now what she expects of me more than I did… we just hadn't been communicating properly… so she started cooking a bit recently… and I'm trying to get finished work a little bit earlier… more recently we've got a better understanding of each other and a bit more upfront and honest with each other' (Kinship carer)*.*

This case highlights the importance of regular reviews of kinship care placements with close attention to the views of children and young people and opportunity for them to feel they can safely disclose any concerns or worries they may have. Assessment of the needs of kinship carers is also critical, as one senior manager reflected:

'We had a sibling group who were with grandparents who found they just weren't fit for it… there's always been that debate you know about standards… I think all Trusts rushed into the whole kinship thing and actually place the children in dodgy enough situations you know which were almost a replica of the situation they had come out of… so we had to fine tune that and determine what's good enough' (Senior manager).

Interviews with kinship carers were conducted for each of the three children living in this type of placement. All kinship carers perceived positive benefits derived from placements with extended family in comparison with non-relative foster care placements, as one kinship carer explained:

'The whole kinship thing is great, and there is support there with the placement and it's good… there is a natural sort of family care there, because

we have always cared for her, since she was a wee girl. I think it is a huge benefit to everyone… and if there's a chance for kinship fostering they should. And when you come to 18 you know those ties won't be severed' (Kinship carer).

Similarly, a birth parent also reflected on their child's placement in a kinship arrangement and reported being happy with the situation:

'Works pretty well and I was happy to have them with my own family members than out with somebody else. My (relative) tells me everything you see what's going on, more than social services. She does everything for them... and they are thriving' (Birth father).

Kinship carers spoke of the impact of caring for the child placed with them and highlighted adjustments which had to be made in their lifestyle to accommodate caring responsibilities:

*'It was a big change for me and to be honest I probably didn't cope amazingly well at the start you know I just kept trying to keep my life as it was. It's been tough at times but now on the whole I think most of it has been quite good, quite positive' (*Kinship carer).

It was clear from such comments that there were some challenges in the early days of placement. For example, another kinship carer highlighted the importance of allowing time for the child to settle into the placement:

'He settled a lot better than I thought he would to be honest, he's really easy to work with, which I didn't think he would be. At the start it was a bit hard for him, but it's only natural' (Kinship carer).

Similarly, the importance of advice and support to assist kinship carers with their new caring role was emphasised. One kinship carer who provided a placement for three young siblings, explained the pressures of the caring role:

'His behaviour, jeepers… when he come to me at the start he was up maybe 15 to 20 times a night… never lay down... and woke up the other ones... I was just sitting at the edge of the bed, that went on I say that went on… a long time and again I'd no help from nobody it was down to me… I was exhausted' (Kinship carer).

Kinship carers had often assumed their caring role because of their family connection to the young person and a strong sense of commitment to their care and wellbeing. However, they did not always have full information about the extent of the child's impairment or how their needs may develop over time. Two of the children in kinship care arrangements were not diagnosed when they came into care. One of these children was diagnosed with autism when he was ten years old and the other child was still undiagnosed despite concerns for their development, as their kinship carer explained:

'Whenever he come to me I just knew things wasn't right… things he should be doing he wasn't doing. And then as he got older I just knew… he didn't walk til late, he wasn't talking... and then he started playschool… really they just knew he was behind... I still think there is a bit of autism… I've always said it to them' (Kinship carer).

Whilst the closeness of fostering within family is reported to bring benefits to children, there are also apparent issues with family dynamics and damaged kinship relations. In some instances, the reason the child had become looked after impacted on wider family relations with kinship carers expressing negative opinions about birth parents. There was a sense of unresolved issues with some anger and resentment towards birth parents and their treatment of the looked after child when s/he had been in their care:

'She always had an excuse to go somewhere… She didn't know how to cope with a baby, she never fed him or changed his nappy ever… She was a funny girl, strange and spoilt' (Kinship carer).

Overall, social workers reported lower numbers of extended families taking on the full time care of a disabled child removed from their birth parents. However, there were examples of extended family members supporting birth parents to continue to care for their disabled child at home. For example, in one case, direct payments were used to enable a grandparent to provide short break support in the family home. In other cases, while social workers had made attempts to explore kinship care options fully, for example, through family group conferences, the offer of full time care was not forthcoming and alternative provision outside the family had to be sought:

'So we convened family group conferences… bringing the family together… to see if there was anybody… and we would provide help with getting you know trying to adapt their home but there was nobody there to provide a home for him… nothing really come out of it' (Social worker).

In these cases, social workers sourced placements for disabled children outside of the immediate and wider family. These included non-relative foster care and residential or specialist care.

3.2.2 Non-relative Foster Care

Six children in the case study sample lived in non-relative foster placements. For two of these children this placement had provided a stable, long-term setting with no disruption. For one of these two children, the placement was expected to remain secure. For the other child there were indications that the placement was at risk of breakdown due to insufficient short break provision to support the foster carers to continue to care for the disabled child. The other four children in non-relative foster care had experienced between two to five previous placement changes, often due to

difficulties in finding a suitable long-term foster carer which resulted in extended or repeated use of short term placements which were always intended to be temporary. Some children had been placed at too great a distance from their birth home or community which put a strain on relationships with their birth families. However, all of the children living in non-relative foster care spoke positively about their placements, illustrated from the following quotes:

'I love living here' (Aaron).

'I just like living here and stuff' (Gareth).

More specifically, reflecting things that children commonly like or need, others stated:

'I like the wee street. It's very good... to play in' (Joseph).

'It's cool here; come in. We have lots of food in this house' (Margaret).

One child who had experience of living in both non-relative foster care and a children's residential home offered the following advice to another young person coming into care:

'*If someone came into care and they had an option between a care home and a foster placement I would probably say take the foster placement. It's so much more relaxed and more lenient if you want to go see friends you can see your friends and you don't get grounded and sanctions and all'* (Alicia).

Most non-relative foster carers of disabled children had a range of previous carer experience. All but one had past experience of fostering children and had previously had offered a home to a range of children in terms of age, length of placement and need. These carers described their motivations to foster with some saying it was for altruistic reasons because they had always wanted to do it, and others because they had not been able to have their own children. One set of carers were in their first experience of fostering, however, the foster mother had previous nursing experience. This child had complex health needs and required considerable nursing care. The couple described how they came to see themselves as foster parents for a disabled child:

'At the panel, with my background I suppose, they suggested we might be interested in a child with disabilities. I was a nurse... going into people's homes with these children with complex needs and tube fed. So I would have met a lot of children like Codie' (Non-relative foster carer).

Birth parents also reflected on their child's placement in non-relative foster care. Some were very pleased with their child's placement and felt that the foster carer provided a high standard of care for their child:

'She's brilliant with him... really, really brilliant with him like... She does everything for him, she is dead on' (Birth mother).

Another birth parent expressed similar views of her children's different non-relative foster care placements:

> *'They're all in good places. I can't fault that. I really, really, really can't. But that is because they had them from babies and they've grew to love them'* (Birth mother).

However, this was tempered by some difficulties in her relationship with the foster carer of one of her children, as she reported:

> *'She isn't talking to me at the minute... which really, really annoys me cos she has my child and I am acting more of an adult than her'* (Birth mother).

Another parent described disrupted and unsettled foster placements which were distressing for her child:

> *'They put her with a foster carer on her birthday which upset her. It upset me. The both of us were in tears because we went out for her birthday and came back and got that phone call that someone was coming to get her in half an hour. She got on well with this lady... she was a nice woman... but unfortunately she was taking someone long-term and couldn't take her. Then she went to a man... but after an hour the man phoned me and she left'* (Birth mother).

Overall, social workers were very positive about the high quality and consistent care that non-relative foster carers (either Trust-based or from private agencies) provided for disabled children:

> *'The relationship with the [foster] family has always been so positive… they just have taken him under their wing... and they love him… they just think the world of him… ever since day one. The foster carers agreed to mum coming down for contact to their home once a week. Between them they created a good bond… it's always been so positive which has really helped everything'* (Social worker).

> *'We have foster parents who take the kids when they're young and they really actually do go the extra mile. They love these wee kids… I can think of two children who had multiple disabilities and were in hospital and we've put in a lot of supports and managed to get foster parents for them and it is phenomenal what these people are doing. One of them doesn't sleep very well and they're up at night, in both cases the mother has had to give up their jobs, the commitment is phenomenal, it really is.'* (Senior manager).

One of the strongest indicators of high quality relationships was seen to be the overall improvement in the wellbeing of the disabled child as indicated in the quote below:

'He has come on fantastic in the placement from when he first went to the placement [about five years ago]. You know he had no independence really but they have done fantastic work with him' (Social worker).

However, social workers highlighted the challenge of trying to source foster carers for disabled children despite incentives such as, extensive training programmes:

'The fostering service have a fantastic training regime and they will look at autism... challenging behaviour... so they offer those services to foster carers but I think it's a big challenge to take on a child with additional needs' (Social worker).

Given above concerns about placement disruption, social workers talked about the finding the balance between encouraging potential carers to consider a disabled child whilst also being transparent about the demands of the caring role. Recruitment efforts were more successful when foster carers had prior experience of working with disabled children, had been given full information about the needs of the child and had a sound working relationship with their social worker as indicated below:

'You're trying to be honest with people cos there's no point in saying to a foster carer this is a lovely three year old blah, blah, blah whenever there are the issues. And it's just trying to get a balance of that... knowing all about the child really helps to make a decision about a child. So I think information is power' (Social worker).

'I have one young person and his carer works in a learning disability centre... and it works brilliantly I have to say... he's a very happy young man' (Social worker).

Senior managers also described difficulties in securing non-relative foster care placements for disabled children, as the following senior managers stated:

'They are very limited, extremely limited in all ways... if you looked at regionally the needs of the population... disabled children or children with autism or mental health needs are consistently not getting placements' (Senior manager).

'We have our own specialist foster scheme... and they are finding it extremely difficult to recruit the kind of foster carers that we need to look after children with these lines of complexity... it is an area we are going to have to work really hard on' (Senior manager).

Indeed, some practitioners reflected on their concerted efforts to support families to continue caring for their disabled child(ren) at home despite concerns about parental capacity because of the limited availability of alternative care placements, as one senior manager explained:

'There are occasions when I suppose the children with disability teams actually put extensive support into a family and wraps scaffolding around the family in an effort to sustain a child within the family and the whole situation, and in doing so we run the risk of actually keeping a child within a situation for too long… Because at the back of our minds we're fairly aware that placements for children with disabilities are hard enough to find' (Senior manager).

The gap in availability of appropriate foster care placements reflected the growing number of children with unique care needs that require a specific skill set from a foster carer:

'We are dealing with kids with much more complex needs with greater levels of medical needs as well as the ASD and learning disability issues... and they are a much more complex group of young people so inevitability we are finding it more difficult to place them' (Senior manager).

However, the following quotes demonstrate that professionals may also be making assumptions about the unlikelihood of foster care for disabled children:

'Some of the things that need to be done are clinical, like feeding systems or epilepsy management... there is a lot of the general public wouldn't take on to mind a child who had unstable epilepsy, nor would you blame them' (Social worker).

'We have a couple of kids very, very difficult to place and very difficult to find carers who are able to cope with that level of complexity just shows us what the parents are coping with to begin with... you simply can't run a family home if every time you turned your head somebody smashes the television or urinates on the floor... professional staff struggle to cope with the behaviours and the presentations of the children, and we have to be very clear that we can't hand that to foster parents and expect it to work when our staff can't get it to work' (Senior manager).

Limited availability of appropriately trained carers could detrimentally impact on effective planning and matching for disabled children, as one senior manager explained:

'We currently do not have enough carers who are trained and are available to do that matching... it quite often comes down to where can we actually get a placement, as opposed to is this the absolutely right placement? I think we're pretty good at looking our stock of placements and saying there's absolutely no way we could place Johnny there either because there's a child of a similar age or with similar demanding behaviour... but we're probably not as clear at saying this is the best possible place for them, so it is more to do with demands and resources' (Senior manager).

Another senior manager indicated that efforts to recruit more non-relative foster carers and short break carers could be more effectively targeted at those who have experience of working in caring roles for disabled children and young people:

> *'Everybody needs to grow their foster parent pool, we need to try hard to ensure that we attract and target the right people... there's loads of people who work in the health service only too willing... I think we should be looking at people... like playgroup leaders... and short break carers... they love it and it's their bread and butter'* (Senior manager).

Some social workers secured foster placements for disabled children through private fostering agencies that now operate in NI including Foster Care Associates and Kindercare. It appears, from the interviews that these services were sought in the absence of being able to find a suitable Trust foster care placement. Whilst these private arrangements were more costly than Trust-based placements, many social workers and senior managers were positive about their capacity to meet the needs of disabled children:

> *'Private foster care placements are horrendously expensive but have worked very well... he carer becomes a professional, giving up jobs because they're obviously fee paying.'* (Senior manager).

> *'Non-Trust private and fee paid carers are actually expecting to take on higher levels of challenge and have different kind of skill sets... and have much more of a professional attitude to the role... that can work very well'* (Senior manager).

There was some agreement that the availability of such highly trained, professionally paid foster carers could be further developed to meet the need for more specialist carers:

> *'We certainly need much more highly skilled and trained specialist foster carers, and then we need to pay people accordingly... there's a need to look at a specialist service that attracts a salary but then we should be having certain expectations of what carers do'* (Senior manager).

However, there was also some concern that such specialist foster care placements were often out of the Trust area removing disabled children from their birth family and local community area. Social workers emphasised the need to develop the extent of specialist foster care available across the region to meet the needs of disabled children coming into care which may help to address issues relating to out of area placements.

However, with greater involvement across private and statutory sectors, there could also be confusion about the various roles of social workers across the private and the statutory foster care sectors, as one social worker commented:

'It can be quite confusing for us... you've got all those roles and it sometimes it can be quite difficult because the parents will look towards you a lot for support when really that support should be coming from the private fostering agency' (Social worker).

3.2.3 Residential Care

Two of the young people in the case study sample lived in residential placements, though these were very different in character. One young person lived in a mainstream children's residential home aimed at young people preparing to leave care and the other in a specialist therapeutic residential community out of jurisdiction. There were also very different views on their placements. The young person living in a residential children's home expressed negative views on her experiences in that particular home. A number of difficulties were raised in the young person's interview, including problems with staff approach and use of sanctions:

'They always treat me differently to everyone else and they always undermine me which is the worst thing. Like I got up yesterday... and asked for my tech money... I was just literally up...it was like 'no, you're on sanctions' and started shouting at me and I came in here and started crying 'cos I didn't know how to react' (Alicia).

There were also aspects of living in a shared residential setting that were difficult for this young person due to her impairment, which she clearly articulated:

'…all this noise and stuff... because of my ASD so I don't really like noise 'cos I can't control this I don't like it… All the staff do is push my buttons… 'you can't do this, that, the other' so then it makes me angry. I like my routine… I like knowing what I'm doing and when and how I'm gonna do it. I don't like when someone ruins it... like they always try and change the rules in here… I don't mind rules but if you're going to change them you may sit down when I come in and tell me... like stopping my routine is not how it works…' (Alicia).

This young person clearly felt that the placement was not meeting her needs, her unhappiness in is summed up in the following extract:

I'd rather be moved about for the rest of the time I was in care than having to live here' (Alicia).

By contrast the young person who was living in a therapeutic residential community reported relatively good relations with staff:

'There are some good workers... really, really good... actually really friendly... and there are systems here like going on outings or holidays that are good' (Adam).

However, Adam did also highlight difficulties:

There are some really simple rules and some are difficult; like you're not allowed to decide what jobs you have to do in the house, sometimes they will choose for you… they will decide for you' (Adam).

In these cases, the young people had developed strategies to cope with the systems within their residential placements. For example, Adam highlighted the importance of compromise:

'You do the things you want to do, you have to split the cake kind of thing, you get half your cake' (Adam).

The other young person reflected on how she had previously used self-harm to cope when she felt that she was struggling:

'Self-harming was a coping mechanism for me it was an easy way to get all the shit out without losing my temper. So it became my way of living' (Alicia).

Her parent talked at length about the inadequacy of residential care and the deterioration of her child's health and behaviour after she moved into residential care:

'It was the only place they could get for her... I don't think staff know how to deal with her and I end up going to the home and getting her up and taking her to appointments... it doesn't really accommodate her... She doesn't do well in group settings… she feels that she is very different and it just doesn't meet her needs… since she went into care, she started self-harming, abusing drugs, she's been arrested I don't know how many times' (Birth mother).

Interestingly, both Alicia and her mother were more positive about a former residential placement, which did not have the same emphasis on preparing for independent adult life. The quote below illustrates her mother's comparison of both placements:

'Looking back in her first home actually they were nurturing more... if she was unsettled, they would have took her for a drive, listen to music, baking... you know, really kind of bonded with her… and it calms her down… but now, in [current placement] I've never once heard her said "mummy I've made a cake"… I've very little input… If I phone to see how she is, it's like an alien concept to them but with other home I could have phoned at any time... and they would have phoned me... With the current place she was arrested and I wasn't told... it had been 12 hours in custody. And she's self-harming and they don't tell me' (Birth mother).

Alicia's current social worker also reflected on how her current placement was not meeting her needs and a care plan towards an earlier move into supported living was underway. However, she also explained the purpose of the home and the challenges for staff working there:

> *'Staff recognise the things she struggles with but it is a unit that has always worked very well with adolescents who are at that stage of moving on… developing those independent skills… and using sanctions along those lines… but those are the sorts of things that she struggles with because she just automatically sees that she's being treated unfairly or differently… for staff, it's difficult because they have to manage a whole group of young people… they have to be fair with everybody… and there have been quite serious assaults on staff by her… they've just found it really hard work… her key worker is a part-time worker… she is very clued in to ASD, to Asperger's… she understands there can't be grey areas with her…. But I think it needs to be somebody who's there more consistently…'* (Social worker).

Senior managers also expressed concerns about how well mainstream residential placements met the needs of disabled young people and called for service development in this area:

> *'I think where you begin to see the gaps is... any of these children going into one of our mainstream residential homes would not work. Even though all the homes have a bedroom that's kitted out for... a wheelchair or whatever. They would just not cope and certainly anybody with learning difficulties in any of those homes, they would get teased, they would get bullied and it just would not work. So they do need to have their own service and it's not there really. It's there for the challenging ones... but there needs to be a lower key service that provides nurturing and understanding'* (Senior manager).

Reflecting the views of Alicia's mother and social worker, managers also highlighted the increased vulnerability of disabled young people in mainstream residential homes to bullying and risk-taking behaviours:

> *'Over the years there has been one or two children in mainstream residential and they've been extremely vulnerable, it's been the wrong place for them, they've been bullied... I would be less sure about how well their needs are met in a residential setting... I think the needs of disabled children are almost forgotten about...'* (Senior manager).

These concerns applied, in particular, to young people presenting with mental health needs or those on the autistic spectrum:

> *'It is very difficult to transform a home at any point in time around the needs of one individual in the context of group dynamics with 7 or 8 children and 3 staff on duty... especially for children with autism for example who need routines and consistency... so the unpredictability of group care settings can be difficult'* (Senior manager).

Some managers indicated that residential staff had been trained to develop their knowledge and skills for working with disabled young people and some homes had been adapted to accommodate their specific needs. However, there was a general consensus that mainstream residential children's units were not configured in a way

that met the needs of most disabled children and young people. In the context of limited availability of foster or kinship care placements, therefore, many social workers highlighted the importance of specialist care placements.

One young person in the case study sample was placed in a specialist therapeutic residential community and another was living in a specialist hospital-based unit. The young person detained in a specialist hospital-based unit had a complex range of mental health and intellectual disabilities and presented with very challenging behaviours. Although he still experienced episodes of being unsettled in his placement and demonstrating high levels of aggression or self-harm, his social worker was positive about the intensive support provided in the unit which had led to an overall reduction in high risk behaviours:

> *'The unit has worked tremendously with that young person... the level of incidents have really calmed down... there's a multi-disciplinary group that meet monthly to follow a particular model for managing aggression....and that has worked very well'* (Social worker).

The young person living in a specialist therapeutic residential community was very settled in their placement, as he explained:

> *'I can't really leave here cos the social workers think that's it's a good place and I think that's it's a good place'* (Adam).

His mother also felt positive about the placement and the support available to meet the needs of her child:

> *'I'm really happy with the help and the support I've got form the social workers and staff where he is now... She always insisted that he was gonna get the help and support he needed and that is definitely the right place for him... I just can't thank them all enough... he could have went to places here or down south but he wouldn't have got the help and support and the treatments and all that he's got over there'* (Birth mother).

A third child with complex health care needs had previously spent a year living in a hospital setting as a social admission. This child was moved to a non-relative foster placement after being deemed by a child psychologist to be depressed due to lack of stimulation and social interaction. The social worker explained that, due to the child's complex needs, a suitable community-based placement was not available and a lengthy hospital admission had been required:

> *'They would have been in and out of hospital so many times in their young life… there'd have been regular discharge meetings and all that back in the day… they were in the hospital for a long time for social admission really because it was impossible to kind of find a place...'* (Social worker).

This child's out-of-jurisdiction placement illustrates the increasing need for social workers to look outside their Trust area to secure a placement, in the absence of

available specialist residential care. Social workers explained that these out-of-jurisdiction placements were required because there was no service available in NI to meet the specific needs of some disabled young people who typically presented with very challenging behaviours, complex health care needs, severe mental health disorders or high levels of risk to themselves or others. Such placements were highly costly both in terms of the placement, maintaining birth family contact and statutory social work visits. Practitioners also reported difficulties when young people aged out of these placements and were at the stage of transitioning into adult services:

> *'The plan for one young person is she will return to NI but the challenge will be an adult service that can meet that need ... one of the fears I would have is that maybe an adult service locally won't be available'* (Senior manager).

Professionals spoke very positively about the standard of care provided in these specialist placements and strongly recommended that such specialist care should be available in NI to meet the increasingly complex needs of some disabled children and young people.

> *'I'm very satisfied with the care that the children have. I'm very amazed at the progress they've made, why can we not do that here in a unit? I don't know, simply don't know... that would make, not just sound economic sense, but it certainly would be better for the care plans of those young children that they are within their own jurisdiction and it makes contact with family and all of that much more feasible'* (Senior manager).

> *'We have three children doing extremely well [in out of jurisdiction]... and I keep asking myself why can they not do extremely well here? But the simple reason is we don't have those facilities here at all... every child that is moved there... is a failure of resources available locally... there is a big gap in terms of a regional service for these young people'* (Senior manager).

3.3 Permanency Planning

As for any child in care, permanency planning for disabled children and young people in the case study sample comprised a number of options including return home, long term foster or specialist residential care, adoption and transition to adult services.

3.3.1 Reunification with Birth Family

Three of the children in the case study sample had returned from kin or non-relative foster care to their birth family. An application to dissolve the Care Order was in place in two instances, in the third the child had always been voluntarily accommodated. For a fourth child reunification was the care plan but recent

developments within the family had led to a re-consideration of risk at home and a shared care arrangement was being explored. Children who had returned home to live with a birth parent were found to be happy and settled, as one stated:

'*I felt good about coming home to live with mummy!*' (May).

One child had a very close relationship with his mother and, since returning home, found it very difficult and upsetting to spend time in short breaks. Indeed, the child's reluctance to go to short breaks potentially threatened the stability of the placement at home which was supported by a relatively high level of short breaks. In this case, the parent reported that she had relinquished her child into care due to insufficient family support and her child had only returned to her when a more substantial support package was made available. This mother described the challenges she had faced:

'*It was a very long drawn out process and it was very difficult... you really have to bare your soul... and it made me feel worse. I wouldn't have went to them and said 'look I can't cope' if there was any other way. And then there wasn't enough families who are even doing the respite for children with disabilities so it took a long time*' (Birth mother).

Each of the parents of the three children who had returned home had made changes in their lives to enable them to provide a loving and stable home for their children. Crucially, these parents talked about the partnership they developed with social services in order to be able to achieve their goal of having their children returned. One stated:

'*It's like, you work with them and they are not that bad, you just work with them and you realise they will work well with you*' (Birth mother).

Another explained:

'*I didn't think they would entertain the idea of me getting the kids returned to me, but I think over the time... how patient I was and how committed they always knew I was, they came round and gradually everything just worked in my favour. Even the guardian from the court – me and her never got on – but she ended up supporting my application as well after she seen me in with the kids, and she supported me then*' (Birth father).

Developing a partnership approach with social workers was a positive step towards reunification with birth parents who described the removal of their children as the single motivating factor in encouraging their behaviour change and co-operation. The quotes below illustrate parental reflections on the positive changes they made to the lives and their feelings about having their children returned to their care:

'*I have done everything I could do to get them back and I have and I'm delighted, really I'm chuffed to bits*' (Birth father).

> *'I started going to women's aid after my trauma... the first time going there was good I felt I fitted in and all it was nice to meet new people and stuff that was going on in my head. And talking about other traumas... it's good to know there's some people out there like you.. I'm now moving onto a journey to freedom... cos I have past all that now... I am just glad I worked through this part of my life, because look where I am now... settled again, better than ever'* (Birth mother).

Social workers also discussed the importance of working in partnership with parents who had resumed care of their children at home, alongside risk assessment, monitoring and targeted interventions to enhance parenting skills. For example, one birth parent completed a parenting programme and engaged in family group conferencing to ensure he had the skills and informal support required to care for his children. In such cases, social work support for birth parents reduced as children settled into their birth family home again and their needs were being well met, particularly when other support services were in place:

> *'We have started to wind down already... before we bow out we will have a meeting and make sure everybody is fully aware of all the issues of the reasons why she came into care. Just for triggers to pick up on for the professionals involved so if things are starting to deteriorate that people can step in very quickly and give mum and the kids the supports they need… there is a worker comes out once a week and takes her out… the classroom assistants would come and take her out… and mum is very pro-active, you know, she's really come on in confidence'* (Social worker).

In other cases, social workers emphasised the importance of continued supports for birth parents whose children had returned home, as one social worker explained:

> *'We're quite fortunate the respite is working well after a dodgy period… hopefully that will continue… because with Mum not having any informal supports these carers would be quite good even as a backup for Mum just emotionally... almost like a grandparent type role'* (Social worker).

There was some concern from social workers that, given resource constraints, the extent of support available for birth families caring for children who have returned home may be reduced:

> *'When you're a looked after child and you're in foster care you have access to fostering achievement resources, independent visitor schemes and other resources... when you're a looked after child at home those resources aren't there… we're finding more and more now we are getting children looked after at home but the resources then aren't there to prop the family up and sometimes that's what people need'* (Social worker).

In this context, social workers described carefully balancing efforts to support birth parents of children at home on a Care Order and monitoring risk, as one social worker explained:

'Having them at home on a Care Order is difficult… they've met the threshold that you share parental responsibility so how are you ever going to remove them if necessary when they're already at threshold? The triggers would be if we're going back to old patterns… it can be disengaging with assessments, watching home conditions… signs of that changing are the times when you go out again and do the multi-disciplinary checks but it can be very difficult to act on... Equally you don't want to take a child who's maybe been in and out already back out and rip them out again from the family home' (Social worker)*.*

3.3.2 Delayed Permanency

In some cases, parents expressed a desire for their children to return home, however, this was often not part of their care plan. When decisions about whether or not a child could return home were still being reached, parents often felt there was unnecessary delay. One parent expressed her frustration at the delay in the return of her child who was voluntarily accommodated in non-relative foster care due to accessibility issues within the family home which she felt could have been addressed sooner with more support from social services:

'This has gone on for 4 or 5 years now… there was a hell of a lot that social services should have did for me regarding the house and all... they expected me to push that myself when they had the power to push it' (Birth mother).

However, this mother also acknowledged concerns about her ability to manage the full time care of her child with complex health needs. The social worker on this case recognised the birth mother's strong attachment with her child but shared her reservations about her ability to cope with the physical and emotional demands of caring for a child with complex physical and health needs. As the decision about his return home was ongoing there were also concerns about disruption to his current foster care placement and the need for permanency, as the social worker explained:

'Mum has went through the motions… wanting him home and then… and then she doesn't think that she will manage him full time... his foster carers are obviously very worried then about the future… could mum change her mind again?... it's working with mum too and making her realise that, as much as she loves him and cares for him, we haven't been able to assess how she really manages him… physically and emotionally' (Social worker).

The foster carer in this case also expressed dissatisfaction with the uncertainty of his care plan:

'You never know where you're at… we have become quite attached to him now and we know that he gets the care that he needs and we worry then whether or not he would get that afterwards… We've been through the mill. There's days I've been to LAC meetings where I came home and I just felt like

crying cos I just thought you know this is all going the wrong direction... you think he's going to be here for a bit longer and then it changes.' (Non-relative foster carer).

Similarly, other social workers commented that ongoing efforts to rehabilitate children with birth family could delay permanency and lead to multiple short stay placements.

'We have an absolute duty to look at family first... and its sometimes been against our better judgement that we have tried those things but the court forced us to... that can lead to some of the multiple placements' (Social worker).

3.3.3 Permanency in Foster Care

Long-term foster placements offered much stability for some disabled children. For example, one foster carer described the disabled child in their care as an integral member of their family and envisaged caring for them well beyond their 18th birthday:

'We got a big portrait done last year and he is in it, and that's the whole family. I like him to be the same as my other children… I wouldn't treat any of them any different… I am hoping he will always be here because it will be like losing one of my children, do you know what I mean? … I would miss him… I suppose when he is 18 or 19 he can make his own decision if he wanted to but I don't think so… he said he would be coming here to live with his wife!' (Non-relative foster carer).

However, other foster carers expressed concerns about the strain of the caring role and the likelihood that they might not be able to continue to provide care in the long-term, highlighting their need for more family support services:

'I've been very taken aback… at really the lack of support… and with a special needs child I assumed I would have the support when I needed it - it's hard and it's 24/7 and it's constant… I'm at loggerheads with them at the minute. It's just really bad… there's nobody to take her… I don't know when I'm getting respite. I don't even know if I'm due that respite... I can't plan nothing, it's just I'm at my end now. I told them that this is going on a year and a half… and if I didn't, I would have to give it up' (Non-relative foster carer).

In most of these cases, disabled children were unaware that they were in unstable placements that could soon end. For example, in the above case, at the time of the end of the study, the carer had requested a meeting with the social worker with regard to withdrawing the placement, however, the child was very settled in the placement, had a close bond with the foster carer and believed it would continue in the long-term.

Interestingly, the foster placements that were most unstable tended to be those that began as a short-term placement and had continued into the long-term. These foster carers had not made a deliberate decision to offer a long-term home to a disabled child and required more support to continue with the caring role, as the following quotes illustrate.

> *'She come to me for 2 weeks and she's with me now for 4 years… I knew it was special needs… but I didn't know what was coming to me - it was a completely new bar... I thought I could manage it for 2 weeks so then the time went on and on and nobody for her and no place'* (Non-relative foster carer).

> *'We did have reservations but we thought well it wouldn't be that bad and it's short term... I think if we had known at the start if they'd said 'look this is a long term placement' we probably wouldn't have went down that road'* (Non-relative foster carer).

In most cases, these foster carers had developed a close bond with the children in their care as time went on and were reluctant to see them move to another new placement:

> *'I had to go to panel to go from short term to long term foster carers and like that too it's nerve racking but… we knew our chances were good… I don't know how I could see myself without having the children around me now either... I mean the first two days they were at school I just sat and cried... kept looking over my shoulder'* (Non-relative foster carer).

However, foster carers assuming more long-term care roles for disabled children also required support. Those who had access to short breaks very much valued this service and described it as a critical support for the care placement:

> *'He goes to the carer a weekend every fortnight… he loves it down there… and it's essential… at the end of the day for a lot of carers is a full time job and you need a break… you can just totally chill out and you're not constantly looking out'* (Non-relative foster carer).

Foster carers of a child with an intellectual disability and complex health needs had acquired considerable expertise in the use of specialist feeding and health care equipment but described how they were at first intimidated by these aspects of the child's care. The placement is supported by a significant package of additional care within the home to ensure the foster family get enough rest to continue their caring responsibilities. The extent of the child's medical care needs and vulnerability to serious illness was not fully described to the carers in advance of them accepting the placement. The carers indicated that if they been give the full picture they may not have agreed to the placement. However now fully aware of the child's support needs and with high levels of support, the family are willing to provide a long term placement because of the loving bond that they have developed with the child which supersedes his list of health needs.

The importance of providing adequate support for foster carers who were caring for disabled children was also underlined by social workers who were very aware of the limited availability of alternative foster carers:

'There are a couple of diamonds out there, couple of absolutely amazing people who are extremely good with children with disability... but we're in crisis as far as foster carers are concerned' (Social worker).

This finding reflects earlier points made by social workers regarding the need to develop the pool of trained specialist foster carers who want to care for disabled children and understand the demands of the caring role.

3.3.4 Placement Change

Nine out of the 15 disabled children and young people in the case study sample had experienced significant placement change as part of their care journey. One young person (aged 9) illustrated the different places where she had lived during her years in care:

'*These are my houses. First my mummy and daddy's house, then my granny's, then a foster carer, then we went to another foster carer, and then the wee flat (assessment centre in black at back of picture) and now at my daddy's house...*' (May).

Another young person similarly described multiple moves:

'*I was shipped about an awful lot. I lived in a foster placement, another foster placement, my mummy, a foster placement, then mummy, then back into care, another residential home and then here*' (Alicia).

Talking about when she moved from a long-term foster placement, one young person stated that she did not have a say in the move:

'It was (social worker) decision to move me, I didn't have a choice' (Shauna).

Parents, foster carers and social workers also reflected on the impact of multiple placements on the child, emphasising that settling into placement became more difficult in the context of multiple moves:

'I think she found it difficult with the amount of changes... then the move to her granny's was meant to be permanent… but then it was me… it took her a while to adjust' (Non-relative foster carer).

'That's really difficult when we get a case at 16 and you look back over the files and you realise how many moves they've had, you know, you just have to sort of stop and think well it's just no wonder they find it so hard to settle you know in placements really' (Social worker).

Social workers stressed that placement moves needed to be carefully planned for disabled children and young people:

'I think it's important that if there was a move that it is planned especially for the children with disability, they need routine, they need structure so I think it's really important that it is planned well in advance' (Social worker).

However, such planning was not always possible if children were moved due to an emergency crisis or repeated breakdown of short-term placements. In some instances there had been multiple moves as social services struggled to find an appropriate, long-term placement for the child.

'One of the things that frustrates us is we often put children in what we have available to us rather than... placements that could meet their need... and children who have gone through a range of placement breakdowns, it's often not rocket science… we knew that wouldn't work there but it was the only placement we had last week... one of the key elements of finding a stable placement is as per their assessed needs is matching them to that placement' (Senior manager).

Interestingly, however, one senior manager explained that disabled children may be less likely to come into care on an emergency basis or move around inappropriate placements than non-disabled children as much effort is made to ensure initial placements are with specialist carers who can meet their specific needs:

'Permanence… is probably better for disabled children because you have to do such a lot of work to even get a vaguely appropriate foster placement that you may have a placement that's more likely to succeed... so they're going into a situation where you've got motivated carers who actually wanted to be looking after a disabled child so… when we do get a placement they mostly

work out… mostly private and people actually expecting to take on higher levels of challenge and have different skill sets and much more of professional attitude to the role…' (Senior manager).

In contrast, another senior manager indicated that there can be an over-emphasis on the child's impairment at the stage of permanence planning:

'The focus was very much on the child's disability, rather than the child's need for permanence and we had to... take a step back, forget this child has a disability, what would be the plan for this child for permanence?… There is definitely a big gap in adopters or foster placements … but there is too much emphasis sometimes on the child's disability' (Senior manager).

3.3.5 Adoption

In only a handful of cases did adoption feature in permanency planning. In one case a child and his non-disabled sibling were assessed for adoption but not freed by the courts so a care plan for long-term fostering was established. This child's parent discussed how the possibility for adoption had been bypassed:

'They can't adopt him. They went through court with that. They can't adopt them both…'cos the way he is and... the both of them had to have been placed together and there was people willing to take (non-disabled sibling) but not him. So then the judge just says 'well I'll put none of them up for adoption then' so none of them went up for adoption' (Birth mother).

In a second case, the care plan was a twin track approach encompassing long-term fostering and adoption. In a third case, a young person had been freed for adoption but adopters could not be identified and the care plan was changed to a long-term non-relative foster placement. However, during this wait for adoption, he remained in an unsuitable short-term, non-relative foster placement for five years. These short-term carers had reluctantly accepted the placement but repeatedly expressed a desire for it to end as they did not wish to undertake longer-term care and felt unable to address the child's challenging behaviours. Interestingly, this child's subsequent long-term foster care placement was a success and his carer offered to adopt him, however he refused the adoption option, as his social worker explained:

'They would adopt him tomorrow in a heartbeat… He told the carer he didn't want to be adopted… he is happy enough the way he is. He just sees himself as part of the family and really he is' (Social worker)*.*

Social workers commented on the challenges of securing adoptive placements for disabled children and young people, often relying then on long-term foster carers, as indicated below:

'In terms of the amount of people who are prepared to adopt a disabled child, it's a very very small number… in my experience it's a situation of a child who

is already fostered and then adopted… in terms of outcomes for the child that's probably what's going to work best… but it very rarely happens' (Senior manager).

'It is much, much harder to get carers who will knowingly adopt a child with a known disability... in my experience if children have been looked after by foster parents it can be very positive if those foster parents then go forward to adopt the children because they've already got used to the level of need that those children need and the amount of medical appointments and things that they're taking them to. And they have accepted them just the way they are and that can be that can be very positive for some children' (Social worker).

'We certainly do struggle in finding adoptive parents for children with a disability. It's not impossible and we have done it, but… adoption is more likely from foster carers… so it's almost like permanence by default rather than pre-planning really' (Senior manager).

Of course, one of the knock on effects of long-term foster carers adopting is that this reduced the pool of foster carers available.

One manager suggested that the age and developmental stage of the child was an important factor, indicating it was easier to secure an adoptive or foster placement for a younger child when the full effect of impairment was not yet known. Others suggested that such uncertainty could mitigate against securing an adoptive placement:

'All children who become looked after are given consideration on the permanence panel… sometimes there's so much uncertainty that a couple balk at it, and whilst they love the child to bits will opt for a long term foster arrangement as opposed to adoption… some of those children are young and small so we don't know when they're going to walk, talk, how they're going to progress through education… so concurrent carers will flounder a bit with that but we do have the adoption support team who do assist and support people very well in arriving at decisions of that nature' (Senior manager).

In addition, the presentation of disabled children for adoption was significant with some managers highlighting the importance of having realistic expectations of prospective adopters:

'We've had two or three children who have been adopted... I don't think it's the word disability that stops it, it's the presentation of the child… at times we do try to pen picture the child and… there are some children's characteristics that would stop people from wanting to look after them, and you've got to be realistic about that as well, because where failure happens then everybody is devastated' (Senior manager).

3.4 Family Contact

The majority of children and young people had some contact with their birth families, with only three children having no birth family contact. In one of these cases, the young person was happy to cease contact and did not want it to re-commence. Another young person also did not want to have contact due to previous negative experiences of birth parent contact. In the third case, contact had ceased and the child was uncertain why this was the case and would like some contact or information about his birth mother. This child was very worried about his mother and, although their social worker had attempted to encourage his mother to engage with contact, there had been no response. This caused a high level of anxiety for the child who returned to the subject several times throughout the interview, stating:

> *'All I want to know is if she's alright and not hurt, that's all I want to know. Then it relaxes my mind if I know she's alright'* (John).

Where contact was planned and regular, most young people reported it to be a positive experience and something they looked forward to. However, there were also challenges related to contact with birth family requiring support from carers and social workers.

3.4.1 Birth Parent Contact

Some of the younger children talked in very positive terms about how they felt when they spent time with their birth parent. For example, one child who was well settled in his foster placement recalled how he felt 'very happy' when he spent time with his birth mother. This child also drew a picture of his birth family contact (see below). It is interesting to note how his mother is central to the image and also dominates it in terms of her relative size compared with others, with everyone in the birth family holding hands:
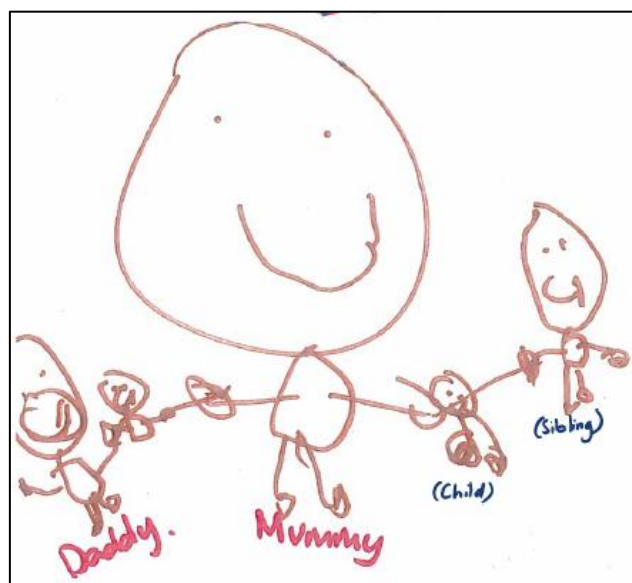
Other children also described feeling 'happy' or 'awesome' during contact visits with birth parents. However, some young people did express concerns about contact. For some, restrictions on the frequency of contact or how contact should be organised were a source of frustration. Young people also described tensions during contact with birth parents. For example, one child described the impact of her father's mental health condition on the quality of the limited contact they had:

'When he is on his medication he is really dazed, like hazy, like he wouldn't really take into consideration what is going on. Like if I went to see him he wouldn't even speak to me, like how are you… see you later, that would be it. That's not even an over-exaggeration, that's what actually happens. But I understand it's not his fault and he can't change the way he is' (Shauna).

Parents also talked about contact and many echoed young people's views on the importance of regular contact with their children however, for some, the frequency of contact was not considered to be enough. The challenge of infrequent contact was also exacerbated for parents by their experience of supervised contact. Families felt under surveillance and, however necessary from a safeguarding perspective, this was clearly viewed as a difficulty for them. As one parent described:

'We see her in the same small room... you can't do nothing... The social worker writes away, writes away... whatever we say, it's written down. Whatever our daughter says, the pen stops... It's never written down. I don't know why' (Birth father).

Some parents talked about problems with how contact is arranged, describing a sense of losing out by not seeing enough of their children and a view that the system works against them, as one mother said:

'I've missed having contact six times this year because of them being unwell and... they're not going to make up the time for that. And I says look if you're gonna do that I'm gonna have to take you to court because that's' not fair' (Birth mother).

For some children contact with a birth parent was reported to be unsettling which was demonstrated in their behaviour following the visit. One parent described contact with the non-resident parent which took place at the child's grandparent's house:

'…his behaviour can be defiant afterwards a bit challenging but I know that's because there's more discipline in this house... there's rules and they push me like they do over at granny's. But I know that that's what they're doing I don't take it personally. And more or less the next day everything's back to normal' (Birth father).

Others reported on contact as a positive experience for the child:

'All I know is that when he sees me and hears me, he be's so delighted, you know, that's my Mummy' (Birth mother).

Carers also shared their thoughts on contact. One carer described a distressing situation when a child who did not have family contact thought that written communication from a birth parent meant his placement was ending:

'He doesn't want to see his mother... she sent him a letter and the social worker read him the letter and after she left... he was sitting rocking and him crying and... he said 'but I don't want to leave here' and I said 'but you're not leaving'... I rang her straight away and she got on the phone to him and reassured him. The next time she came out he said he didn't want no more cards, no more presents but we agreed for one Christmas card every year' (Non-relative foster carer).

By contrast, other carers described contact as relatively unimportant to the child:

'It doesn't bother him going or coming back but he doesn't ask for it... over the summer he didn't get at all and it didn't bother him' (Non-relative foster carer).

Non-relative foster carers recognised the importance of maintaining the connection between the child and birth family, with some going to great lengths to facilitate contact. For example, in one case of a child placed out of Trust area, contact relied on the good will of foster carers who drove a long distance to bring the child to contact and waited all day whilst they had contact, as they described:

'We take him.... there's not a wild amount to do there during the day... so it's quite a long day... that was a big commitment... initially we only thought it was going to be short-term... but then you couldn't stop once that had been established' (Non-relative foster carer).

Other foster carers talked about how they worked hard to maintain the link with birth parents in other ways, besides contact, as one described:

'In their bedrooms we have photographs of their mummy and of their siblings. We say good night to them at night and god bless them and all the rest of it' (Non-relative foster carer).

Social workers and managers also described the efforts made to support contact when it was appropriate. Primarily, social workers were guided by the direction from the courts in relation to contact arrangements (including necessary supervision) and undertook a range of preparatory and debriefing work to support the child to engage positively in birth family contact:

'Generally contacts are laid down by the court... some of the contacts have to be supervised... it's very time intensive... it is a big piece of work and keeping all of the carers on board... for children with learning disability there is an enormous amount of preparation to prepare youngsters... lots of visual, lots of

photographs... and making books and diaries and social histories... and debriefing afterwards, the kind of winding down and talking about what happened' (Senior manager).

Social workers and senior managers were also acutely aware of the challenges of maintaining contact with birth family, including the impact of child or parental impairment or ill health:

> *'Contact is very inconsistent and that can also be because those parents have a disability and their capacity to maintain relationships is very limited...'* (Senior manager).

> *'The children get sick. That's the biggest challenge we have especially where the parent wants to see all children together... It can be cancelled at the last minute and then you're running into try and get that contact set up again so that's always a challenge... it's a logistical nightmare'* (Social worker).

In addition, young people's fluctuating mental health could impact on family contact. For example, in the course of the research one young person experienced a deterioration in their mental health which meant reduced visits to his birth family home.

In situations where contact worked well, foster carers facilitated the arrangement and had a good working relationship with the birth parent which helped the child to feel even more settled. In order to ensure that contact arrangements were safe and meaningful, social workers stressed the need to organise contact on a case by case basis because some children and their parents may require additional support or arrangements may need to be reviewed, as outlined below:

> *'The contact was facilitated by the grandparent... 'as-and-when' the family wanted to arrange it... but then there was a really bad contact where there was an attempted assault and contact hasn't happened that way since'* (Social worker).

Social workers reflected on the fine balance between acknowledging the rights of parents to have contact with children versus the negative impact the arrangements can sometimes have on children:

> *'You can have very traumatised children you know they remember a lot... about parents... they will pee the bed or become traumatised but then that is part of their identity and they are the parent'* (Social worker).

> *'He was very, very angry a lot of the time about being in care and that sort of came to the fore when they had family contact… I remember one day he was screaming for the birth parent to go away... and sometimes siblings wound him up and he just wouldn't be able to deal with it…'* (Social worker).

3.4.2 Sibling Contact

In three cases children shared their placements with siblings. Four had siblings who were also in care but in a different placement and five children were the only looked after child in their family with the siblings not being in care (three of these children had no siblings). Some young people spoke of contact with their siblings, often in conjunction with discussions about parental contact as it tended to happen at the same time. It was clear that sibling contact was important to children and young people. One young child who saw her siblings together once per month looked at pictures of her family during the interview and kissed the images of her siblings. This child also made a drawing of herself with a sad face and then added a picture of her sister beside her and changed her own frown to a smile (see below). Even for this young child it was clear how important her relationships with her siblings were to her.

However, there were also challenges for sibling contact. For example, one young person was not allowed to visit her siblings in the birth family home due to safeguarding concerns, which meant she was only able to see them formally once or twice a month. Another young person wanted to have contact with his brother, but to date this had not been possible.

Parents also talked about the importance of sibling relationships. One talked of her pleasure at being informed that her children (previously in different foster settings) were going to be placed together in time for Christmas. Another happily recalled contact when she is together with all of her children who are in different foster settings:

> *'It's all of us like together. Then we go out somewhere nice'* (Birth mother).

Carers also reflected on the importance of sibling contact. One foster carer reported that the child she cares for expressed an important nurturing role when he spent time with his younger sister:

'He loves caring, he has a very caring nature and he enjoys seeing his little sister particularly' (Non-relative foster carer).

However, in another case, the carer commented on the difficulties of facilitating meaningful contact for with sibling:

'He had much less contact with him, and it would also be kind of short... 'cos after a short time it began to deteriorate… he received a letter recently from him so I think his brother wanted to make some contact so we are sort of trying that out in principle' (Non-relative foster carer).

Social workers also stressed the importance of siblings remaining in contact with each other and the foster carer's role in supporting these arrangements was critical both in terms of acknowledging the importance of siblings and by offering practical support. Some arrangements were informal with the foster carer of one child hosting contact for siblings at their house. For example, one carer described facilitating contact between three siblings:

'When the three get together they get so excited seeing each other... they see each other maybe twice a week... like we're going to the cinema... or the fair together as a group. At Christmas the other foster carer organised Santa Claus going to her house so we do it for the three' (Non-relative foster carer).

On other occasions, sibling contact was more formal:

'They have contact four times a year with... I think it's enough... it keeps that identity and relationship and it's what he wants' (Non-relative foster carer).

3.4.3 Extended Family Contact

A number of children also enjoyed close relationships with extended family. This was more often the case for those who lived in kinship placements or those who were looked after at home on a Care Order as these children had the opportunity to have routine informal contact with wider family. Interestingly, social workers reflected on the challenges, in kinship care placements when family members facilitated contact that could compromise children's safety:

'Contact is very important because there's such a significant relationship there... at times there have been difficulties with the grandparents colluding with mum... we've found out that the birth parent maybe has been seeing the children behind social services back so it's always trying to negotiate and encourage the grandparents to be honest about that' (Social worker).

Another young person drew up a list of her birth family and all the people she would like to have together, including her immediate birth family and wider family members. When asked why she had included all these people in her drawing she simply stated:

> '*Because they are all my family*' (Aoife).

By way of advice to others, one young person underlined the importance of family contact:

> '*Probably one of the things that I would advise anyone who comes into care ever would be if you have contact with your family don't throw it away*' (Alicia).

3.5 Disability and Identity

Some young people talked positively about their sense of self, for example the young person quoted below commented on how she is seen by others:

> '*Well the majority of them say that I'm doing quite well like I adhere to all the things I'm supposed to adhere to. I'm quite a well-mannered girl and like I'm quite a strong personality*' (Shauna).

Another young person described their sense of self in a very positive light, selecting a 'very happy' feelings face to represent how they felt about themselves.

Most of the case study interviews incorporated reflections on children's impairment experiences and the impact of impairment on the child, family and care placements. In addition to the experience of impairment, another key aspect of the identities of disabled looked after children was their connection with birth family identity and their sense of a care identity.

3.5.1 Impairment Experience

The children and young people participating in the case studies had a range of impairments, including intellectual disability, autism, physical or sensory impairments and/or mental health needs. In addition, some children and young people presented with complex health care needs or severely challenging behaviours.

Younger children did not have a strong sense of identifying themselves as disabled and only a few articulated their identity through the prism of impairment. When asked how they saw themselves, many of the young people chose personality traits such as chatty, determined, short tempered, scientific, polite, friendly or happy. However, some did have a deeper understanding of their impairment and shared their views on how it impacted on their lives. For example, one young person discussed the impact of receiving a diagnosis of ASD as a teenager and reflected on the delay in her diagnosis:

'My Mummy always knew when I was a child that I wasn't right... like from I was two, she knew... that I wasn't like the rest of my brothers and sisters. So in a way my Mummy always knew there was something there... and when I was seven she took me to a specialist to try and get me diagnosed with something to try and get better and then I was diagnosed with dyslexia which didn't really explain a lot and still wasn't the cause so eight years later I got diagnosed with ASD... in a way it was a good thing but it completely wrecked my life... like when I was diagnosed it was always everything bad like 'you can't do this, you can't do that, you'll not understand this, you'll not understand that'. There was never positive… it was like 'you'll never you won't understand jokes unless they're very, very, very simple. You won't understand people's facial expressions' (Alicia).

This young person was taken in care because her behaviours were beyond parental control, however her previous behaviour may have been understood differently if she had been diagnosed earlier as being on the autistic spectrum. Her parent explained that being diagnosed with ASD during adolescence was challenging for her daughter:

'Her big thing is 'I've been diagnosed with ASD' and I try to explain it to her she's had this all her life and just because she's just recently had this diagnosis does not make us think or feel differently towards her, she's still the same. I says you're letting ASD define you rather than you define ASD... she just thinks she's stupid... she can become very, very down on it...' (Birth mother).

This young person's social worker also highlighted the importance of early identification of impairment in order to secure the right type of services at the right time and the consequences of delayed diagnosis for this particular young person:

'I just felt it was a real shame that she didn't get the diagnosis until last year really because it seemed like there could have been a lot of really good work done when she was younger and more open to that work... she has struggled with how she's felt about life and relationships and social situations all these years and now she's] finally got a diagnosis… but all those frustrations are still in her and a lot of damage has been done in terms of family relationships and the worst of it all being that she has ended up in the care system' (Social worker).

Another child spoke of how he felt others saw him and made a distinction between how he was viewed by adults in his life compared with peers at school, based on their understanding of his impairment:

'Mainly adults find me pleasant to be around but other pupils find me repulsive and they don't find me really like the way other adults think. The pupils in the school believe that I'm just bonkers, crazy... let's say mentally retarded' (John).

However, he views his own identity quite differently to how he thinks others see him:

'I'm like an observer. I find out ways I can help people. I'm very medical as well. I would like a profession in science... I want to observe people and how they can like improve themselves... they're like my lab rats... I just say to teachers try this out and it actually works' (John).

Parents and carers talked about children's impairment related needs emerging as they grew up and moved on to school, with some also reflecting on the need for earlier diagnosis:

'He just looked like a normal child. He has nothing about him to say like nobody could turn round and say that child has a disability… I think they knew before he started school that he was slow at picking up stuff like kids of his age but then when he hit school that's when everything came out… then he had to go on the medication and he settled' (Kinship foster carer).

Indeed, for some children, a diagnosis remained elusive even though they firmly believed the child had an impairment, as one kinship foster carer described:

'He used to line things up and they said that was down to global developmental delay because of his age and he wouldn't be just as bad. But there's just still some wee things he does that makes me think there's still something there, like in terms of autism… but they said he is too sociable' (Kinship foster carer).

For children who had been diagnosed, some parents and carers reported the child's impairment in terms of deficit:

'No, no she can't read and can't write' (Non-relative foster carer).

Others described the complexity of the child's needs but also emphasised positive aspects of their lives:

'You could write a book about him... He was born early.... he has been in hospital over a year... and in intensive care, on life support... so it has been hard.... you've just got to keep your eyes on him all the time... you have to change his nappies.... do his physio with him and the peg feeding... but it's very easy done... he's doing really well health wise now... overall he's a very happy child. He's just a typical wee boy... you know we can see his personality coming out and he can laugh and he can get up to badness, you know, like a typical wee boy' (Non-relative foster carer).

Some foster carers talked about how the children in their care had come to them with a list of things they were not or would not be able to do with an emphasis on deficit, but they had been determined to counter this and encourage development, as one carer stated:

'We were told you know that she may never be able to feed herself, may never be fit to talk... and I thought no she will! I was determined she is going to do it and I was going to be the person that was helping her' (Non-relative foster carer).

Social workers also commented on the identity experiences of disabled looked after children. Interestingly, some social workers highlighted the issue of dis-identification whereby disabled children or children with mental health needs preferred to disassociate from disability or mental health services, as one social worker explained:

'Many children in CAMHS don't see themselves as disabled so... they need to be directed to something that is appropriate... in fact you will have children making very discriminatory comments like 'I'm not going there, they all have a disability' ... because they're seeing the physical attributes of the disability and they don't have those issues so therefore they don't see they should be there' (Social worker).

3.5.2 Impact of Impairment on Care Experience

Parents reflected on the impact of impairment on the reason for their admission to care. One parent clearly indicated that the reason their child was in care was directly related to their impairment, stating:

'If he didn't have a disability, he'd be here, I know' (Birth mother).

Another parent stated that, had it not been for her child's impairment and complex health related needs, he would not be looked after, recognising that she was able to care for her other non-disabled children still living at home.

Several parents described the difficulties they experienced in coping with their child's behaviour before they became looked after, and the perceived lack of support within the home.

'We always had advice on behaviour but no-one coming into the home to give us practical help with it or being here overnight to give us a break. We were exhausted and it was emotionally draining. When he kicked off... I was left to bear the brunt of his violence... and he also used to run away' (Birth mother).

This experience is mirrored in accounts given by other parents. In particular, parents often identified a time when their child's behaviour escalated. One stated:

'On her second birthday, it was just like someone flicked a switch and this angel went and this little devil appeared' (Birth mother).

For others, adolescence was a key time when behaviour deteriorated and birth parents became less able to manage their child as they physically grew. However,

these parents also conveyed a sense of not being listened to, of their concerns that *'something was not right'* not being taken into account:

> *'I took her everywhere. I took her to my GP, I took her to behavioural specialists, I took her to a doctor at the clinic who then said she was dyspraxic but I knew there was always something underlying and nobody would listen'* (Birth mother).

Another parent considered how the situation at home may not have escalated had they known more about how to offer support to their child within the home, she stated:

> *'Nobody knew why he behaved like that and then he went and got assessed... and he had Asperger's and a learning disability, ADHD as well... but it wasn't caught on when he was a young child... he was round about eight before it was caught on. Where maybe if he had been caught on you know when he was a baby at one of two it would have been more help and he might still be at home you know. Things mightn't have got as bad.'* (Birth mother).

Foster carers also discussed the challenges they faced in caring for a child with more severe levels of impairments or complex health needs. Carers talked of their fear in the early days of a deterioration in the child's health status or *'that something would happen'* while the child was in their care. As one carer with considerable prior nursing experience stated:

> *'I had to do exercises with her at home... but she was that fragile like you were afraid to move her'* (Non-relative foster carer).

Caring for a child with complex health needs also impacted on other children in the foster home, as one carer stated:

> *'…the first while he was in hospital that was hard to cope with for the girls 'cos one of us had stayed with him all the time and... he was in hospital for weeks so that was quite draining on us'* (Non-relative foster carer).

However, as time went on carers became more relaxed and confident in their ability to provide adequate care. Foster carers also had access to courses which supported the development of knowledge:

> *'There's so many courses... first aid courses, drug courses, alcohol courses.... I thought 'oh my goodness really these symptoms I'm learning today really tick boxes in my house' you know'* (Non-relative foster carer).

Impairment also impacted on the type of care placements available for disabled children and young people and their experience of living in various settings. For example, for young people with deteriorating mental health or behaviour or with more severe levels of impairment, placement choices were more limited and specialist residential placements were often sought.

3.5.3 Birth Family and Care Identities

Knowledge of life story, connection with birth family, understanding parental impairment and making sense of a care identity were important aspects of identity. For example, one young person discussed at length what she understood about of her parents' mental illness and the potential impact it may have had on her own life. She recalled how she was first told about their illness:

> *'I was told at such a young age, I probably shouldn't have been. I mean I was told at seven or eight... and it really freaked me out… My social worker told me about the actual illnesses and what they were called and I was like so confused… They told me that schizophrenics can hear voices telling them to do things, but obviously they don't know if that actual symptom belongs to my parent or not. They were just going from the actual illness and what she could have... I was thinking am I talking to myself or hearing voices or what? I was young and I used to freak out about it'* (Shauna).

As time passed Shauna became less worried about her own health as she matured and her understanding grew:

> *'I don't have it because you can tell by someone's behaviour and there's tell tale signs, like by my age now you would have known. So it's a bit of a relief'* (Shauna).

Within the context of such complex identity issues, social workers highlighted the importance of life story work with disabled children in care:

> *'Life story work is so important with these kids... the foster carers have their treasure boxes... and the clothes they came in and their first shoes and pictures of Mummy and all that. I think that's really important… I was going through photographs in our old camera and came across a photograph of them at contact and I got a copy of it and brought it out to them and they were just like I had given them a thousand pound... they were absolutely over the moon so photographs and contact and knowing who you are it is really important'* (Social worker).

Similarly, another social worker explained:

> *'We had a life story book which the young person found really, really useful and would still bring it out to show people on occasions… He was quite proud of it … and developed some insight into the reasons why they were in care'* (Social worker).

Social workers were aware that disabled children and young people may need support to help make sense of who they are. This is well captured in the quote below:

'Well that young person is… under psychiatry at the minute… but I'm looking at talking therapy to compliment that because the issues are to do with her identity, wanting to go home, adolescence and trying to make sense of these issues... the same issues that come with all LAC children... and the same insecurities and you know the low self-esteem... disabled children have the added pressure of disability... so it makes it more complex in a way...' (Social worker).

Birth parents also reflected on their own life stories and their own childhood experiences of abuse and out-of-home care. One father, for example, talked about the impact of his own adverse childhood experiences and how his alcohol dependency had impacted on his own parenting experience:

'I was brought up in foster care... and I was told that my Mum killed herself because she didn't want us... she drowned in an accident... but I was being brought up by a drunk foster carer and told that it was my fault... I was physically abused as well mentally abused... they wondered why I turned out as bad as I did for so long... really... a lot was then to do with my alcohol abuse but... it was five years there since I had a drink' (Birth father).

Another parent talked about her own experience of impairment:

'Learning difficulties I have. I've had it from I was from wee... I'm alright it's just forms I can't fill them in' (Birth mother).

Parents also talked about the impact of the loss of their child when they were taken into care and their concern about the impact of growing up in care on their children:

'I feel desperately sorry for her because from when she went into care, she's had no childhood... I really do feel that it was to her detriment to go into care… they've destroyed my child's childhood' (Birth mother).

This feeling of deep loss due to the separation from family was echoed by her child, illustrated in this parent's account of a recent LAC review meeting attended by both of them:

'The last LAC I went to, she ended up crying and I ended up crying with her. She was like "Yous took me away from my mummy and I can't see my brothers and sisters." I'd actually to take her out of the room' (Birth mother).

These findings emphasise the importance of direct work with disabled children and young people who have experienced a disruption to their personal and family identities due to being removed from their birth family homes. Indeed, there some very good examples of life story and narrative work in the case files of some disabled children and young people in the case study sample.

3.6 Everyday Lives

Children and young people were asked to describe their weekly activities. Most attended school and some talked of subjects they liked and of other interests and hobbies. Many young people talked about their friendships and some also discussed the difficulties they had experienced due to bullying by peers.

3.6.1 School

Disabled children and young people talked of their school experience in a way that might be considered typical of any child. Older children talked more of their favourite school subjects whilst younger children described activities they enjoyed:

> *'I like baking cakes and being out where the flowers are and playing inside the class and dressing up'* (Aoife).

> *'My interests at school are ICT and science'* (John).

For one child, school was an important part of her sense of achievement and control of her current and future path. She described how an experience of bereavement as a younger child shaped her approach to her school work:

> *'When I was younger and [close relative] died, I just really focused on my work… and then the next year I got a wee award for being the best in my year. When something like that happens you realise that you don't have all the time and you should make the best of what you have'* (Shauna).

For some children, school experience was affected by changes in their care placement. For example, one child had to move school due to being placed in an out-of-area specialist foster care setting. This child had attended a special school where therapies could be delivered on-site, however, there was no such educational facility close to their new placement.

Parents and carers also reflected on children's experiences of school. For some, school was reported to be a very positive experience:

> '*He loved school, he still likes school. Wouldn't be the brightest but he's getting there, he's doing all right'* (Kinship foster carer).

Others talked about difficulties experienced at school, for example, one foster carer discussed challenges for a child placed in a mainstream environment:

> *'In the old school they couldn't cope with him 'cos he wouldn't sit... he was eating soap, and he was eating sand, he was doing everything…'* (Non-relative foster carer).

However, a change of school saw a resolution to these challenges where smaller class sizes and more tailored learning was enabling the child to settle and make progress:

> *'The new school is more suitable... there's only six or seven in his class this time. But he's like completely settled. It's very much geared to child's needs... it's all the sensory stuff, specific teaching. All of his speech therapy, occupational therapy, that's all done in school'* (Non-relative foster carer).

Social workers generally perceived disabled children's experience of school as positive:

> *'The school is very good... he would run about… does horse riding and he loves swimming … He's doing really well'* (Social worker).

Most social workers highlighted schools as an important source of academic and social support for disabled children and some described working collaboratively with staff in schools.

3.6.2 Activities and Interests

Outside of school, disabled children and young people talked about their involvement in a range of activities including playing sports or computer games and watching television. One described themselves as a '*typical teenager', stating:*

> *'I like watching TV, I like girls, I like climbing trees and I like animals a lot... and I like people and reading books'* (Adam).

Others talked about contact with family and friends when not at school. Overall, young people described busy lives and engagement in a wide range of activities and hobbies.

Some social workers drew upon a range of local voluntary initiatives and schemes in creative ways to support disabled children's social opportunities, particularly in the summer period:

> *'We're very lucky here… for the whole of the summer last year she was out nearly every week doing some kind of activities... their summer scheme... wee Saturday clubs… the leisure centre here would have an integrated summer scheme but has the support too'* (Social worker).

The importance of carers with knowledge of how best to facilitate disabled children's participation in social opportunities was highlighted, as one social worker stated:

> *'He does go to local youth club and then he refuses after a while but the carers would be very good with him... In the youth club his carer was a helper and that made a difference... he mixed in well'* (Social worker).

This is further highlighted below where the social worker also drew attention to the importance of having staff at social and leisure opportunities who are disability aware and trained to meet the needs of disabled children:

> *'We tend to only be able to use youth clubs where there's staff disability awareness training, extra volunteers or maybe a buddy system in place or... additional supports there'* (Social worker).

Social workers understood the importance of supporting leisure and social opportunities as a means to address the potential for social isolation that some disabled children in care might experience, as indicated below:

> *'Social isolation can be a big factor for children who are looked after and who are disabled... Special Olympics and other things provides massive support for social isolation... and it also provides a bit of respite for the family which is much needed'* (Social worker).

3.6.3 Aspirations

Young people talked of their hopes and dreams for the future. Many framed this in terms of educational or employment opportunities, one said:

> *'Well like I am definitely going to university'* (Shauna).

Another talked of job plans: '*I'd like to work in Asda, doing the shelves'* (Margaret).

Two young people were ambitious to work in the police force and, for a third, there was a clear influence of her care experience on her future hopes and plans:

> *'I was thinking of like helping people. I wanted to be an adult social worker or... someone people can talk to... or do something like take kids out and do fun things with them and like let them speak to you and stuff'* (Shauna).

Another, responding to her care experience of living in composite settings and dropping out of school, simply said:

> *'My dream would be to live by myself and to have my qualifications'* (Alicia).

Parents and foster carers also talked about young people's hopes for the future, some seriously considering options for the child and adopting a positive approach:

> *'He has always wanted to be a police officer, so he is interested in cadets and we talk about that quite a lot... I think he has a lot of potential to achieve quite a lot'* (Non-relative foster carer).

'I'm just thinking about further education and how she wants to move on with that because she's quite bright, does well in school. She's got a natural ability... she talks well, she listens well' (Kinship foster carer).

Others took a more dismissive attitude:

'I don't think there's anything she says she'd like to work in ASDA but there'd be more eating done than working' (Non-relative foster carer).

However, it was recognised by some carers that negative attitudes can present significant barriers to disabled young people's opportunities and underestimating their abilities can hamper their potential, as one foster carer stated:

'I think people are very quick to write them off, they think they don't have no potential... you know look at all his problems sure what's he gonna do? What's he gonna achieve? Whereas he is a great wee man' (Non-relative foster carer).

3.6.4 Friends

Disabled children and young people spoke very positively of their relationships with peers which were clearly a very important aspect of their lives. A lot of friendships revolved around school and many talked of having a large group of friends and the activities they do together:

'*We would go to each other's houses and have sleepovers and stuff or like go to the cinema'* (Shauna).

'We play in the playground and we play at my friend's house' (Aoife).

Others had a more limited circle of friends and talked of one best friend. For some disabled children and young people, social relationships were centred around their care setting, particularly those in residential settings. For example, one child named members of staff in their placement as their friends. Another young person talked of her closest friend being another young person in the residential unit in which she lived:

'He has been here all the time I have lived here... we have been mates for quite a while' (Alicia).

Parents and carers also reflect on the child's friendships reporting a busy social life for some children with lots of friends and activities:

'*She's got friends here she's got clubs four nights a week and they've more social life than I have'* (Birth parent).

Another reported a more restricted social network with friendships confined to school environments:

> *'He has friends like at school, but he doesn't go out with them'* (Non-relative foster carer).

One foster carer highlighted the challenge of securing necessary support in settings to enable the child to engage with social activities:

> *'Social outlets, we could never secure that – we tried to with Praxis and Autism Initiatives but never got it because we need 2:1 staff'* (Non-relative foster carer).

In addition to friendship circles, issues relating to personal relationships were emerging for some of the older young people. Social workers were aware of the need to provide sensitive support to disabled young people around their sexuality and personal relationships and how challenging this could be in residential care settings. This was highlighted in the example below:

> *'There's an ongoing concern about personal relationships… all the young people are very aware that they're not allowed in each other's rooms, particularly not at night... it continues to create attention and then that just escalates in the evening…'* (Social worker).

The birth parent of the young person in mainstream residential care expressed concerns about her vulnerability to manipulative personal relationships, describing a previous relationship she had with a peer in the home who had encouraged her to engage in anti-social behaviour.

3.6.5 Bullying

Several of the children talked of their experiences of bullying, although this was amongst the older children. For some, bullying had been an ongoing, serious problem that impacted on their educational opportunities and continued to have a significant negative effect on their lives:

> *'I got bullied at school in first year, second year and third year. Bullying is something that has populated my entire existence, cause at primary school I was bullied for seven years. We told the school and they didn't do anything, they said it was just kids having a laugh, but those seven years and the additional three years have been the torment of my life... Some people might have good lives and plenty of friends and they'll be more sociable and there's another life for people who have got bullied so long that their whole life and existence was nothing'* (John).

Another when asked about how being bullied had impacted on her life, stated:

'… my mental health, I have anxiety, paranoia and depression' (Alicia).

A number of children reported that their experience of bullying in schools was exacerbated by the school not dealing with the problem:

'There was an incident last week and they haven't done anything about it' (Shauna).

'The schools I have been to are not tackling bullying. We still live in a generation where you can't escape it' (John).

Some children talked about how they tried to draw attention to the problems they were having but to no avail:

'I tried to make them aware of it by saying I was going to commit suicide in school. I was going to give hints but not actually do it. I typed into the computer – how many people have died or committed suicide because of bullying? They just said that was so negative of me' (John).

One child reported being expelled from school because of challenging behaviours which were, from her perspective, in response to long-term bullying:

'I got chucked out of school. They just decided to pick on me when I was young, 'til fourth year, then my temper burst and I got kicked out of school. I didn't actually do anything I just ran about and used to go out for smokes all the time, and they sent me to the principal's office' (Alicia).

This young person also had undiagnosed ASD during her school years and reflected back on how her behavioural response to situations in school was linked to her impairment which was not known or understood by school staff or peers.

There was some discussion about disabled children and young people's experiences of bullying amongst parents and carers, although children themselves were more vociferous on this subject. One kinship carer described ongoing issues with bullying for the child in their care and, whilst there was support from social services to deal with bullying problems, the carer felt that the child had been let down by the school. Strategies to cope with bullying had only been generated through social work support and the input of the kinship carer. Within the school environment, staff had not taken incidents of bullying seriously and the child did not feel they had received action or support required.

Another birth parent described the context of her son's bullying experiences of school:

'He sort of was more of a loner, he was happy just playing with cars and trucks by himself. Then when he started school the school environment didn't suit him.... he liked being on his own and obviously being in a class other ones and they sort of picked up that he was different. He didn't want to play with them and he got bullied...' (Birth parent).

This birth parent described how bullying at school had fuelled problems that her child was experiencing at home prior to becoming looked after. In response to the challenges he experienced at school, his behaviour deteriorated at home which his mother felt contributed to her inability to continue to care for him at home whilst also keeping her other children safe:

Social workers were also concerned about bullying that disabled children had experienced both in school and in the community:

> 'She's been bullied throughout the years… she would say that she's struggled a lot over it and would hear nasty comments from the other children across the road... some of the kids in school would pick on her and give her a hard time about it... and so she's had to really try and be very, very resilient about it and just try to stay strong and not sort of retaliate to these comments cos it would be very hard for her' (Social worker).

These comments from social workers, parents and carers highlight that school responses to bullying are often inadequate leaving disabled children and young people vulnerable to persistent bullying which has a lasting negative impact on their lives.

3.7 Being Heard

Disabled children and young people gave mixed reports as to whether or not they felt listened to or had a say in decisions about their lives. A range of structured processes were in place to afford disabled looked after children the opportunity to be heard including LAC or school reviews and meetings with their social workers. However, the extent to which these processes actually facilitated hearing the voices of disabled children and young people or offered opportunities to influence decisions about their lives was variable. In addition, given the bullying experiences reported above, it is important to consider who disabled children and young people have to turn to if they need someone to talk to about issues in their lives.

3.7.1 Involvement in Decisions Affecting their Lives

Many of the children and young people were aware that their LAC reviews were a forum in which decisions about their lives were taken. Few of the younger children attended their LAC review and one reported that she was unsure what the meeting was for, so her father attended:

> 'I don't know... Daddy does, he knows what those meetings are for' (Aoife).

Another young person reported having attended their LAC review once at the stage of leaving care:

'I only went to one LAC review… about transferring me to 16+' (John).

One young person talked about her mixed experiences of participating and influencing placement decisions:

'Moving from my last placement was my own decision cause my social worker wanted me to stay there, that was my own decision. Moving from my {kinship carer] I didn't have a choice... but there wasn't much space so I sort of had to move' (Shauna).

One young person reflected on being involved in the decision about returning to care after a short period at home with her birth parent:

'…it was sort of easier to come back into care. I'm used to all this caper and I suppose my mummy didn't want to take the decision so I said it was better for me to go back into care' (Alicia).

Although sometimes listened to and involved in decisions, this young person spoke of her frustration when not being listened to:

'People not listening to me is one of the biggest things that pushes my buttons, it is like people purposely pushing my temper, yeah, I don't like that' (Alicia).

This young person gave an example of a social worker who had not listened to her, although she reported that she now has positive communication with her current social worker:

'Some social workers never listened, they never listened to a word you said and that made it worse' (Alicia).

Another young person reported that while she is listened to, she is rarely asked for her opinion and sometimes is not offered any choice:

'…like people do listen, but sometimes they don't ask... sometimes you don't get a choice, sometimes the foster carer would be like you are doing it' (Shauna).

Parents and carers also reported mixed experiences of children being listened to and included in decision-making. One foster parent explained the satisfaction they felt the young person got from being part of decision-making processes, as she explained:

'He generally likes to take part... my feeling would be that he does genuinely seem interested and he asks about it and he knows what time we are meeting' (Non-relative foster carer).

One parent underlined the importance of listening to the perspectives of children and young people to enable child-centred decisions. However, some felt that impairment

may negate the child's ability to have a real say in decisions affecting them, as one parent said:

'Well with his learning difficulty he would make a decision about himself but I don't think he would make best decisions. He would want to do what he would like to do and he would like not to go to school every day... because of his learning difficulty I would really need to make the decisions for him... he has his own wee mind things he wants to do and that's fine but common sense would have to come into it' (Birth mother).

Some parents also reflected on how their child's preferences are overridden because of the wider needs of the family. For example, one parent relied on short breaks to enable her to continue to care for her disabled child, alongside the needs of her other children. She explained that, whilst her disabled son would prefer not to go to short breaks, it was an essential support for the family:

'Even for respite, I know it's a good safe environment you know although he'd rather stay with me. It's very, very important for our whole family 'cos it keeps us all ticking over you know' (Birth mother).

Social workers also reflected this issue of asking disabled children for their views but not being able to deliver on their expressed wishes:

'You're asking a child, 'what can we do to make things better for you?' And what they're telling you, you know you can never do. And that's really hard as a social worker because you know you're nearly setting this child up then to say by the way 'sorry that isn't gonna happen'. It is quite difficult and sometimes as a social worker I may not always ask that. Because I think we're walking away and giving them a false hope especially if it's something like returning home' (Social worker).

Interestingly, a kinship carer explained that children may not talk openly to professionals about their true feelings due to concerns that their disclosure would lead to an over-protective response and, thus, concerns about real problems could be withheld:

'Nearly all kids under care of social services would be very guarded in giving their opinions and their thoughts and feelings... they're automatically a bit guarded and a bit cautious about coming forward because they've maybe said something and it's caused a sea change in the way that they are dealt with or the way their lives are allowed to continue and I think that's very common. Big changes can happen as a result of someone just letting off steam' (Kinship foster carer).

This comment is a reminder that social workers need to facilitate open channels of communication with disabled children and young people in various care settings and work in partnership with children when deciding on appropriate responses to their concerns.

Social workers were fully aware of the need to ensure that the views of disabled children and young people were sought in all matters affecting their lives. Some social workers referred to the contribution forms that are used to ascertain children's perspectives prior to LAC reviews. However, other social workers highlighted the limitations of this method of involvement for disabled children:

> 'There are pro formas for contribution forms that go out… none of them really take into consideration disabled children... I suppose that's down to us to do a more bespoke one if needed...it's down to the individual to be more creative and at times you can forget... if you're doing so many visits you can go in with your pro forma and it works for maybe the majority of your caseload. But no until you'd even raised that question I hadn't thought that actually our forms aren't fit for purpose for some of our disabled children... there's no real consideration for that' (Social worker).

While highlighting the challenges of involving children who have complex needs, social workers were also able to reflect on the creative approaches they had been developing. For example, one social worker highlighted recent progress made in their Trust area:

> 'We are really working towards involving disabled children you know if they're able to attend the LACs and... arts, you know, to sort of just take it from the individual child what way would work best for them so… there definitely is some change around including the child's view…' (Social worker).

Another social worker described her creative approach to seeking the child's views for LAC meetings:

> 'I would sit down and play with them... They know the routine we have… I would say first… I talk to Mummy and then we do the hands. And they know that I draw their hands and it goes from there' (Social worker).

Similarly, senior managers highlighted examples of innovative participatory practice:

> 'In our residential short breaks we use a booklet prepared for each LAC review that is a more formal opportunity for the children to say what I like, what I don't like, what I'd like to see changed etc. what my wishes are... I insist that the visits will include times when the children will be home from school so that children are seen in their own environment with and without parents... in schools, transition workers will actively engage with young people about their future plans and we use a mapping process like the yellow brick road starting with where we are at and where they want to go on their journey' (Senior manager).

> 'We are very aware of participation and we're actively trying to get children to participate more in the LAC reviews. We're beginning to use iPads and there's an app called 'Mind of My Own' and our Social Workers can go out and go through this with the kids. Now we're finding that we've been able to

use that with kids with disability and they've responded to it quite well. So we're looking at ways to widen their participation and to try and, you know, grow their understanding of the position they're in and care plan and have a voice. We also changed the format of the LAC review and the child's views are presented first' (Senior manager).

However, social workers persistently highlighted lack of consideration on how to effectively involve all disabled children in decision making and limited access to specialist training in this area. Senior managers were also aware that there still room for improvement in relation to involving disabled children in reviews of services and decisions affecting their lives with a reliance on carers to represent their views. In addition, there needs to be emphasis on the time and effort required to build relationships with disabled children and young people, as one senior manager explained:

'It still comes down to relationships... and the time that's required to get that... there's a timetable of statutory requirements to perform LAC reviews... and you end up, out of necessity, fitting the child the family around your rota and if the child doesn't fit in the rota and communicate in the forum then the child in quite often left out or their views are translated through another medium sometimes not very well... I think probably children with disability are another step behind LAC children in general... with a lot of things including resourcing and bringing their voice to the fore is probably lagging a bit behind' (Senior manager).

Levels of participation were affected by child's impairment but also the attitude, knowledge and skill of the worker:

'It varies depending upon the child and the social worker involved with the child... there are some children who we can't actually get an engagement with cognitively... very rarely these children are at LACs because they just wouldn't be able to cope with it, so we wouldn't always see... the voice of the child booklet... and it can vary depending on the knowledge bank and skill of the worker... some social workers are very creative and will make an arrangement to sit down with the child and will ask the speech and language therapist to be there, you know so that there is a distinct piece of interaction about child's thoughts, feelings, wishes, hopes... some folk have been doing this for a long time and now have found themselves at a point where they are able to do those solo' (Senior manager).

Most social workers and senior managers, however, indicated that further attention to alternative communication strategies is needed:

'One of the things that we're becoming increasingly aware of is the importance of understanding how somebody communicates... there is a need to develop communication tools... pictorial representation... it's just a simple thing that you can overlook but it could make a massive difference' (Senior manager).

Indeed, some senior managers indicated that they had identified the participation of disabled children as a priority for further development in their area:

> 'We have not been particularly good historically at involving disabled children... we're working with speech and language therapy and with some voluntary sector colleagues to try and overcome some of those things... it's always a challenge to work with children who have communication deficits but that's no reason to not do it... so I think we're not very good at it... we've kind of decided that's a deficit and we need to do that... and put some money into it' (Senior manager).

3.7.2 Counselling and Advocacy

Young people identified various people in whom they could confide if they had a problem, including teachers, social workers, foster carers and birth parents. Most young people were also able to comment on who they would turn to for different types of issues. For example, one young person said he would talk to his teacher if he was *'a sleepy head',* but if he was feeling sad he would talk to his mother.

Only two young people talked about accessing formal counselling services. One young person had ceased counselling services because she felt there was no benefit as her counsellor did not get to know her personally:

> '…obviously the counsellor has been informed by my social worker everything that has happened in my life so she is just reading me off a piece of paper. Like she doesn't actually speak to me for me, she is just speaking to me for what is on that piece of paper. So I'd been going for about four weeks and... it was like over and over again, like repetitively… there's no point in going over things and getting upset about something that happened four or five years ago. It's pointless, I didn't get any benefit from it... so I stopped going' (Shauna).

Similarly, a carer echoed this child's views of counselling services:

> 'It was bringing back old memories and digging up in the past instead of looking to the future... it wasn't working for him' (Non-relative foster carer).

In contrast, another young person was accessing counselling from a voluntary organisation and was positive about the opportunity to access this independent service:

> 'I started the counselling off my own back for a bit of support to talk about how I'm coping in here without in here knowing… it's a whole lot easier than having to talk to someone who deals with in here… she knows I live here and she knows all about the staff and everything. So it's a bit more support having to cope with living here and not wanting to be here' (Alicia).

None of the children and young people in the case study sample had experienced access to independent advocacy services. However, social workers described other cases where children's advocates played important roles, particularly for young people who present with challenging behaviours or high levels of emotion which sometimes meant that they could not attend their meetings. However, although social workers indicated that some professional advocacy services were available, there was a consensus that these could be further developed and tailored to the needs of disabled children and young people:

> 'That's not great and we are in the process with working with VOYPIC to try and develop advocacy services.. we need to do more of it and get better at it' (Senior manager).

3.8 Social Work Support

Social workers have a key statutory role for all children in care across placement types. Disabled children in this study had contact with a range of social workers including placement related social work (e.g. foster care link worker or residential social worker) and fieldwork social work from LAC teams or children's disability teams. Given the range of social work involvement, diverse social work roles were described by children, their families and social workers themselves. A critical aspect of effective social work practice highlighted by most respondents was the importance of relationship between a social worker and a child or young person and their parent/carer.

3.8.1 Social Work Roles

Children and young people described the activities their social worker engaged in, including home visits and outings. As the quotes below show, children and young people often appreciated when social workers spent time with them and engaged in one-to-one direct work with them:

> 'She's nice… we play, talk sometimes about all different stuff' (Aoife).

> 'She's awesome… she does work with me' (Margaret).

> 'I like her… she takes me for something to eat' (Connan).

> 'She does help… she tries her hardest, she really does' (Shauna).

Social workers were also key sources of support at significant times of change in the lives of children and young people. For example, one young person planning to leave care stated:

'I'm trying to get out of care so I've… a panel placement meeting… and she's helping me with that' (Alicia).

Birth parents described a range of roles their social workers had played in their lives, including advice on parenting, listening, providing information and offering practical or emotional support, as the following quotes illustrate:

'She was telling me to… get him to sit and talk cos he wouldn't at all… just telling me how to deal with him' (Birth mother).

'We've had different social workers but any of them I've had have been more or less helpful… They've always told you, you know, what's going on with him… They would let you know if he's done something wrong or if he's sick or if he's run away… they do keep you pretty well informed' (Birth mother).

Several birth parents reflected on their understanding of why social workers had intervened in their family life:

'It gave me more of an insight into what social workers do you know obviously there was good reason why they came in and stepped in' (Birth mother).

However, for other birth parents, their accounts of engagement with social work services were mainly negative, often due to feeling a lack of control over social work decisions to remove their children from the birth family home, as the following quote illustrates.

'My mind was all over the place and I never slept… and I couldn't eat. And I if I was my right mind I wouldn't have let them… they don't give you your rights until it's too late… they wanted the children from the start' (Birth mother).

One parent felt that social workers had been too risk averse following a false allegation and had failed to take time to consider the evidence and the wider family context:

'One of the social workers had this witch hunt …she made the situation a million times worse… saying that I had abused her badly and trying to put her on the register for confirmed abuse and… everyone else around the table said they couldn't do it in a clear conscience because I hadn't been interviewed… and the police doctor found there was no marks... the police basically dropped the case that day. There were no charges to answer... and then the next day, her social worker was taken off the case' (Birth mother).

One birth father felt that social workers focused too much on birth mothers to the detriment of his children and reflected that social workers only began to listen to his views when they realised placement with their mother was no longer feasible:

'There were different social workers… they seemed to want to put me down more than they did with her… they were more interested in the mother with the wee ones than the father… I definitely had more to prove… but they

should be there for the two, you know... the wee ones looked to me like they're starved... I says 'you're not even doing your job as you're more interested in her… the wee ones are starved, they haven't even got fed'… when the wee ones was took off her they started to listen a bit more, you know, they stepped back and they listened' (Birth father).

Some birth parents indicated that social workers could provide more practical and emotional support for parents:

'He would have come out and you know chatted and… suggest different things which you try or you've tried and you know won't work… but that's all the help they give you, really you need more maybe practical help and support.' (Birth mother).

'I have to be everything to everyone so I have to keep myself stable but when she was going through that black bad period, there was no support for me and I was actually frightened to even turn round and say to social services and even when I did there was none… not even when the health visitor rang social services and explained the state the family is in and that we needed help that day' (Birth mother).

Birth parents emphasised the importance of being listened to and having an opportunity to have a say in decisions about their children's care plan, as the following examples illustrate:

'Whenever I first felt pressured by social workers it was absolutely horrible… they're telling you this and that and they want you to agree with that. That's wrong, you know, I should have my opinion and my opinion should be heard. I think it's very important for a parent who has a child in foster care to be heard... and be able to talk about their child and what they want for their child and social workers to help them and give them the best advice and support possible whether it's to get their child back home or whatever... I don't think my voice was listened to at times' (Birth mother).

'My experience with social workers wasn't always favourable… but all the social workers this time worked well… I wasn't knocking heads with them… if you've got a grievance you can air it and work through it' (Birth father).

Carers also outlined various social work roles including: understanding their family needs; advocating for access to services; listening; and offering advice in a non-judgemental way. For example, one foster carer commented on the crucial role their placement social worker played in terms of practical support to maintain the foster care placement:

'We couldn't have done it without the social worker because he was battling away… the one thing that's been consistent throughout all the whole time and kept us guided and who communicates a lot for us with the different social workers… he has been brilliant. Even at the start, you know, keeping us right

because we were so naïve… we didn't know we could have more support… but he fought our corner, took it out of our hands and dealt with it… got it all sorted that we'd have to have respite because he knew if we weren't getting respite that the placement would have just stopped. This placement wouldn't have worked only for him' (Non-relative foster carer).

However, as the quote below indicates, other carers also suggested some social workers could provide more support:

'Some are absolutely wonderful there's some could maybe do a wee bit of work on that... we would very much distinguish, when we would say 'She's a really good social worker'... it's more the listening. It's more the sort of working with you. If you have an issue telling you if you're not doing something right and telling you in a nice way and showing you another way you can maybe do it better' (Non-relative foster carer).

3.8.2 Relationships with Social Workers

A key factor impacting on the effectiveness of the social work role is relationship. Most children and young people described a positive relationship with their social worker, for example:

'I get on well with my social worker… we are actually really close… usually I tell her if something is starting to annoy me' (Shauna).

'She's good… she talks about different things… like how you feel and stuff' (Gareth).

Indeed, some young people who had developed close working relationships with their social workers commented on feeling sad about ending contact with them, as the following young person explained:

'I'm moving over to the over sixteen team... but before I do like me and my social worker are going to go out for food or something… Probably the next time I see her will be the last time… it's sad that I won't see her but I'm ok like' (Shauna).

However, children and young people could also identify social workers who were less effective at building good working relationships. Another young person compared the positive relationship with her current field social worker with the lack of relationship with residential social workers in the home she lived in:

'The support that my social worker would offer me would probably be a lot better than what I get offered here [placement]. If I text her and I'm like 'listen I need a bit of help, this is getting too much', she's there. She's just like 'right I will come see you when I can'… whereas if I say here 'listen this is getting too much' it's 'go sit in your room'. There's just no in between, there's no 'right

give me five minutes and we'll have a chat' or 'come on, we'll go for a walk or a drive to clear your mind'… but my social worker would take me out when I am a bit stressed and she would talk to me and try to tell me like just to try and pull myself back and try and not let it get to me' (Alicia).

Similarly, another young person described more limited investment in relationship from previous social workers:

'I had another social worker before and I didn't like her so I asked for her to be changed. She was not very good, like we would ask her to do something... like to speak to someone, to do something – she would never do it' (Shauna).

Parents and carers also talked about their relationships with social workers and the services they offered. Many parents and carers talked positively about the support they received from social workers, including regular communication and trusting relationships:

'She is a particularly good social worker. I'm very fond of her and she works well with X [child], she works well with me, she works well with the rest of our family. She'll always ask about the family, you know, she's very tuned in to the needs… there's an understanding and if I need her I know I can contact her and I know she'll give me sensible advice, I've a lot of respect for her' (Non-relative foster carer).

'She's been brilliant… you have no worries… I could ring her after 5 o'clock or if anything happened through the night; I have her mobile number... if she doesn't answer she will call straight back... I would only phone if necessary so she knows it's important' (Non-relative foster carer).

Parents and carers valued social workers who took time to get to know their family situation and who displayed a caring approach to the job, as one carer explained

'I've met a lot of social workers... and there are some you just would say are spot on, they're really good social workers. And those really good social workers are ones that care. They come in and they have an understanding of a family setting that you're taking children into your own home… with your own children' (Non-relative foster carer).

As parents and carers encountered different social workers over time, they were able to reflect on those who were more effective at forming good working relationships:

'Her initial first social worker, I just found that there was very little involvement. She just called and said hello how's things? Ok. ok. And there was very little else... her social worker now has been one of the better social workers she's had. She connects a bit more with her… I think she's been good on the whole' (Kinship foster carer).

Social workers who conducted statutory visits but did not invest in relationships with children and their parents/carers were deemed to be less effective as they had a more limited understanding of how best to support the child within the wider family context and the needs of carers.

> *'We have had different social workers for the kids across Trusts and sometimes social workers just come in and they'll speak to the kids, they'll do what they have to do, and will speak to you very briefly and will be out through the door again. And I know that that's sometimes is needed as well. But sometimes I feel that they didn't listen to my point of view on things that have happened and the circumstances'* (Non-relative foster carer).

For foster carers, lack of consideration of the wider needs of the family had potential to impact on the success of the placement:

> *'You maybe have issues with your own children... there are social workers that come in here with a total disregard of what was going on for the rest of your family.... at the end of the day it has to work for the family as well… I know their main interest is in the children and their needs but I think they need an all-round view of what the child and family are coping with and what we as parents are coping with...'* (Non-relative foster carer).

> *'Listening is a big part of it… sometimes I would have felt that social workers thought they have more of a power... you were just the foster carer, you didn't really have a say... there needs to be a bit of respect that you are looking after these children that need a lot of care and it's an important job… it's also important for us that you return the calls... I could wait three days to get contact from the social worker... That can be little things that is missed out on, you're not kept informed with some decisions that you maybe should have been informed of... it's not just the professional side that needs listened to it's the carer's side as well'* (Non-relative foster carer).

Carers also emphasised that social workers should recognise the value of their viewpoint based on their experience of caring for children or personal knowledge of the family:

> *'There's also been incidents that have happened through failures especially for social services… like contact with Mum… I says 'I don't think it's such a great idea at the moment because she can be quite volatile'… and they says 'oh no this is what's best for the child'… and they went ahead and created a meeting and that went very badly… despite us saying we don't think the time's right… we knew mum wasn't right for it… and I was quite annoyed... you know they knew better… I think the will is always good but a lot of it is has come from text books'* (Kinship foster carer).

A recurrent theme in interviews with social workers and senior managers was concern about the shift towards social workers being viewed as service brokers. Senior managers emphasised the importance of encouraging social work staff to

recognise their specialist skill set and important relationships with children and families, as the quotes below illustrate:

> *'Social work is becoming a care broker... we had fallen into a bit of a trap… under care management arrangements... and in child care social work there is a concern that there are call centres where social workers direct people to various services… but we're trying to get back to staff seeing themselves as a profession… a return to our very clear specialist roles... the ability to be a change agent, to be a support to have a massive impact on families. I don't think at times that is totally acknowledged or understood… or valued or promoted enough by the social work agencies themselves... sometimes we need a bit of confidence in social work'* (Senior manager).

The depth of the social work role was also emphasised in terms of providing emotional support for families of disabled children based on close working relationships and holistic assessments of need and risk:

> *'It's not just about the care package, it's about stripping back some of the difficulties that parents of disabled children have and doing that work and I don't think that that's always recognised or understood by other professions or other social work teams… our social workers are not just brokers of care packages… you actually strip down the whole emotional caring role of the parents and get in there and see yourselves as a resource working with those parents'* (Senior manager).

Working in Partnership

A sensitive and non-judgemental approach grounded in partnership working was highlighted by parents and carers:

> *'She will always listen and she'll say if she thinks something's right or something's wrong... but she wouldn't condemn me… she said 'look perhaps we maybe need to think about another way that we can sort of work on it for later'. She wouldn't say 'you know that was the wrong thing to do'… we could have a wee chat, maybe see if there's anyone else can give you any other pointers… just a very gentle approach, very nicely'* (Non-relative foster carer).

Indeed, some parents reported a turnaround in their relationship with social workers when they had taken a partnership approach to working with social services, as one stated:

> *'I rebelled against them… but whenever I got myself back on my feet again my eyes were starting to open… Once I started working with them, they started working with me and we became friends… if it wasn't for them I don't know where I'd be... I hated them at the time but now it's like if anything's on*

my mind I would phone her [social worker] for advice... if it's anything to do with the kids… yeah it's a big turn around like' (Birth mother).

Parents found it easier to cooperate with social services when they felt that social workers were working alongside them with a shared view on safeguarding concerns and the best interests of their children. The benefits of such partnership working were clear, particularly for parents who subsequently had their children returned to their care, as the following two parents explained:

> *'It was always the ultimate aim for me and the social workers... and then to know that they would still support me even after what had happened, it was absolutely great... they didn't feel that the kids were safe which I fully understand... I says 'no I'd have probably done the same if I was in their shoes'. And that's the way I looked at it...'* (Birth mother).

> *'I knew that the social workers would do their best by the kids and that was ultimately what I wanted so we had the same goal'* (Birth mother).

The key foundation of a positive partnership working between birth parents and social workers was honesty and transparency, as the following quotes illustrate:

> *'Sometimes you get missed communications from them… I just want them to be truthful with me and I'll be truthful with them'* (Birth mother).

> *'Just to be honest and straight forward with everyone instead of keeping anything back, that's the only thing I don't like… just tell the truth about it all… and try to give as much advice and support as you can… I am working with social services now but… at one time I was afraid to tell them anything… I suppose I was scared to open up but now I'm not. I open up quite close with them and they open up quite close with me and tell me things what's going on'* (Birth mother).

This approach was important for all birth parents and, particularly, for those whose children were voluntarily accommodated. One parent emphasised this point and highlighted that the parental role continues well beyond their children's contact with the care system:

> *'I'm her mummy and I'll never stop being her mummy and like I said to the social workers when they were giving me a hard time, I understand that they put her in care. I understand that I have to now trust my child with these people but at the end of the day, I'm her mummy and long after these people go, I'll be her mummy so I want the best for her'* (Birth mother).

Similarly, social workers emphasised the importance of working in partnership in order to support parents to meet their children's needs in a non-stigmatising way. As one social worker stated:

'You can't really work with the child without working with the parents cos they know them the best effectively so you have to… respect the parents. They know their child the best. And give them that I suppose authority in that way... the whole family has to be on board and has to be assessed or else you'll not be able to make one change in the family because the rest of them will not come along with you' (Social worker).

3.8.3 Social Work Staff Changes

Inconsistency in social work support was an issue raised by several parents and carers who felt that it was difficult for both them and the child to work effectively with social services when there were multiple changes of social worker. One parent reported:

'They chop and change, chop and change, and chop... he's only eight and he's had about ten different social workers... it's frustrating for the kids cos it's like new ones coming in all the time with them, it's not fair like. They should just keep the one social worker instead of loads and loads of different ones' (Birth mother).

A carer recommended an approach to address this issue:

'Probably be best having the kids to be shadowed by another social worker instead of just having the one so that say someone goes on maternity or has to leave in an emergency at least the other one can pick up from there... and these two social workers are communicating about their caseloads and it is a face, a person that the children would know and more importantly they would know about the children... it would be a good thing... I'm sure those changes are as difficult for the social workers as it is for the child sometimes' (Kinship foster carer).

Children and young people also talked about having different social workers and a few were unsure of the name of their more recent social worker, as one young person explained:

'She has dark hair cos we only met... I haven't got into the personality things yet... she had to go early but I'm sure I'll see her throughout this year' (John).

Similarly, some parents and carers described a series of social work staff changes and a few were unsure who their child's social worker or keyworker was at the time of interview:

'Her keyworker, I've met her maybe twice. They're meant to meet but they haven't actually set a date' (Birth mother).

'The social worker left to get married. Then there was another one left social services. There's another woman but I never seen her. Meant to but I haven't seen her so I don't know' (Birth mother).

'Her case load was all changed and we were taken off it and then he was given to Y [current social worker] and now I think a new one might be taking over but I don't know for sure yet' (Non-relative foster carer).

Children and young people also recalled periods of time when they did not have an allocated social worker due to staff changes:

'She was off for like a year and a half so... no-one stood in. I didn't have anyone' (Shauna).

Multiple staff changes impacted on opportunities to develop working relationships with social workers and left some families feeling that they were missing out on services as they had no-one who knew their case to advocate for them, as one carer explained:

'The social worker should've had respite sorted out instead of passing the buck to somebody else when she moved on....It's just sorta the buck is passed from here to there' (Non-relative foster carer).

3.8.4 Training Needs of Social Workers

A final challenge for social workers was securing access to bespoke training particularly in relation to the effect of different types of impairment and communicating with disabled children. For example, one social worker commented:

'There hasn't been training... our team don't have that specific knowledge of maybe the specific disability... I would love it if we could access that... even just on a consultation basis cos I would love to know more about learning disabilities and how that might impact them upon their future development cos there are things that I don't know' (Social worker).

Senior managers also recognised training gaps for social workers working with disabled children across child care and disability teams, as the following comments illustrate:

'Generally our LAC staff would depend on children's disability in terms of co-working and wouldn't do direct disability training... for example, residential staff may or may not have expertise in working with disabled children but then sometimes disabled children will be placed in residential units... and in terms of children's disability understanding more about the LAC world… it's a two-way street across a lot of thresholds and all of those interfaces' (Senior manager).

85

In the absence of such training, staff relied on informal co-working to access specialist knowledge about impairment effects or sources of support.

Social workers in LAC teams who are not trained in disability issues may struggle with their responsibilities for disabled children, particularly if they cannot access advice or support from children's disability services for these cases. This was often the case for undiagnosed children or children with mild to moderate levels of impairment or ASD. However, senior managers overseeing LAC services were clear that if staff identified a training need impacting on their job performance, suitable training could be secured:

> *'Under supervision processes if someone is identifying their limitations, it should be noted… if people are genuinely saying I can't do my job... or I will do my job better if I could go to this, I think it will be organised through a very clear process… I don't feel our staff are excluded from anything'* (Senior manager).

Likewise, some social workers had the opportunity to raise training needs linked to issues arising from their caseloads, however, disability-related training was not always available:

> *'In the past, I've been able to do things that have been specific to cases I've been working on... if there's a specific need in a team, the training team would come and deliver some training in team meetings... I have actually been looking out for some training on ASD... there hasn't been anything recently'* (Social worker).

In addition to training for social workers in different teams, senior managers highlighted some difficulties in facilitating multi-disciplinary training due to separate training systems:

> *'The system is set up as a uni-disciplinary training system. The social services training team is social care, nursing training is separate again and sometimes we have difficulty getting multi-disciplinary training...   and   that's something that remains a challenge for us... we would certainly welcome other disciplines… nurses or AHPs to   join as well so it's not always uni-disciplinary'* (Senior manager).

3.8.5 Current Challenges for Social Work Services

Several of the birth parents and carers reported a sense of social work services being under pressure due to increasing demands, limited staff resources and service cuts. In the context of these challenges, some birth parents and carers empathised with their social workers, as the following comments illustrate:

'I just know she's a lot on her plate, you know, very busy and the whole social work team is under-staffed... it must be really difficult for them. I wouldn't like to do that job' (Kinship foster carer).

'They've either been inexperienced with huge demands on them and if they have more experience, the better they are at the job so the more is put on their plate. I think that is that is a problem and it's indicative throughout public services... I do get the feeling the whole system's very stretched' (Birth father).

'I know it's a hard job. I wouldn't like to be a social worker so I'm not condemning them in any way... they're getting it from all angles... the foster carers, the natural parents, the kids quite often maybe aren't happy and they also then have their colleagues as well. Social work is not an easy job' (Non-relative foster carer).

Working in a climate of austerity was a consistent theme, as highlighted earlier in the report, in interviews with social workers. There was a general view that limited resources ultimately resulted in families not being able to access support when they most needed it:

'Families are really having to be pushed to their breaking points before they're eligible for services because the bar of eligibility for services just keeps getting higher and higher and as a worker that's frustrating… we would be pushed to close cases where there's no services going in. That's not to say that the family don't need or want services that's to say that we're not providing any services. So therefore close it' (Social worker).

The lack of focus on preventive services resulted in some families not being supported at particular pressure points, such as, post-diagnosis when families are adapting to new caring roles or transitions during adolescence or into young adult life:

'There's different points in a disabled child's life where for a multitude of reasons … things just become very difficult so it can be after diagnosis, it can be the birth of a new sibling or a family bereavement or a behaviour change. Puberty, school changing... you know life events that are difficult for any family can be exacerbated really if you've a child that needs a high level of care... sometimes closing cases you're maybe not being there to pick up on... little stresses slowly building up. We suddenly then get them back as a snowball, complete crisis' (Social worker).

Social workers recalled cases when they had sought preventive support for families in need without success, as indicated below:

'You go to your panel you ask for… maybe a direct payment for two hours a week and you're turned down... you try to source some respite in a club but most mainstream clubs aren't suitable... or there's no availability, all these services are completely bottle necked because once parents do get a place

they don't let go of it until their child is at the upper age limit and has to leave... we then see the parent trying, asking for help and we're not providing it' (Social worker).

In such situations, social workers were concerned that the pressures on families could build up as they become worn down which can lead some parents to seek a care admission for their disabled child, as one social worker explained:

'I've had a few cases where parents have been just completely pushed to the limit where they have wanted their child to voluntarily come into care because they can't cope... the parent has been at suicidal point… it just makes me sad and frustrated that anybody had to be pushed to those levels to get the support that they were asking for maybe six months a year or two years before' (Social worker).

Whilst, help may then be offered in response to such crisis situations when children are on the edge of care, there was also a concern about the lasting impact of families 'being pushed to the limit', as illustrated below:

'I worry about the lasting effect of that on families with children perhaps feeling then that my parents were going to put me into care… What would that do to a child's self-esteem and belief if they felt their parent was so burdened that they tried to give me away or... take their own life because they can't cope with me? It's horrific... if you try and place yourself in the shoes of either that parent or the child' (Social worker).

In addition to limited resources, social workers highlighted the impact of reduced staffing and higher caseloads:

'I had over 100 cases. It was an absolute disgrace. Now I'm down to 30 – 40…but I think the burn out rate will be huge and it's doing our kids a disservice' (Social worker).

Senior managers also emphasised the lack of adequate investment in children's disability services, particularly in comparison to other health and social care services in NI and funding for disabled children's services in other parts of the UK. Such restricted resources mitigated against creative or collaborative working and reduced access to services, as the following excerpts highlight:

'Children's disability services come out of a very under resourced world where we're working with very high caseloads, with very little time and the opportunities to be creative are limited... and how do you deliver joined up working in a poorly resourced service?' (Senior manager).

'Austerity is driving so many things… it just pushes so many things that people compartmentalise, people reduce things down to the simplest and they exclude people from services cos they can't afford it and I think child with disabilities suffer from that' (Senior manager).

3.8.6 Working with Other Social Work Teams

Social workers understood their role within the structures of their particular team, such as children's disability teams or LAC teams but were also aware of different organisational practice across teams and Trusts. Disabled children known to more than one social work team could have several different allocated social workers for varying periods of time due to a previous history of social work involvement or multiple presenting needs. In some of these cases, co-working across children's disability and child care/protection teams provided some consistency for families, as the example below shows:

> *'We've very good co-working… LAC reviews are held jointly and there's good core group working… very good interchange with children's disability, you know, like alternate minute taker for the LAC team… or they assist each other with statutory visits… the two teams are geographically very close and there is very clear working relationships there in one particular locality'* (Senior manager).

Others found it beneficial when, for new referrals, mainstream children's services undertook the court application as it allowed for a 'fresh start' with children's disability services untainted by the court proceedings:

> *'They transferred over to us once the court and all that was over which actually worked out very well from the point of view of having two different social workers because… it's very difficult to have a relationship with someone who you've taken their child off... it is much easier to have a relationship with someone when you're starting afresh and you're focusing on the needs of that child rather than on what had gone before'* (Social worker).

Furthermore, some social workers indicated that such arrangements allowed social workers in children's disability teams to focus on support needs whilst others with more expertise in child protection could lead on court proceedings. However, these views were not shared by all social workers as some highlighted tensions in shared roles and concerns about multiple social work involvement, as indicated below:

> *'I'm from the children's disability team so basically we wouldn't have a statutory responsibility for LAC... so there could be at least three or four different social workers... that causes some issues because we might have a lot of awareness of a child, the situation, the family background... yet we don't have a lot of say when it comes to the child who has been handed over to a new team...'* (Social worker).

> *'In general they work very well but… you do invariably get some tensions… people can be at times very conscientious and precious about their roles and it can sometimes be very difficult times for workers who can be struggling to help families or a placement stick together'* (Senior manager).

Senior managers also reflected on these challenges and the decisions about which team was best placed to take lead responsibility for a disabled looked after child. There was a general consensus that, despite clear policy direction, the roles of each team can become blurred in cases where disabled children are already known to children's disability teams and the expertise of their social worker is utilised, as one senior manager explained:

> 'The boundaries aren't very clear…. in our policies and procedures it does say, that if a child protection issue arises then that should be co-worked with a FIT team but that's not always the case because if the child is known very well to the disability service then they'll just run with that… do their own child protection work and court work' (Senior manager).

In the context of unclear roles and responsibilities, the extent to which team leaders and managers could negotiate tasks and resource implications was critical:

> 'Co-working is heavily dependent on good relationships and working arrangements between the team leaders… the main thing is that the team leaders all have to talk, then a plan can be put in place with jobs' (Senior manager).

> 'I would have to say it depends on which senior you get because some we can have very good sensible operational conversations with and some we can't, so sometimes you end up having to slug it out... … it really does need to be thrashed out on an individual case by case basis' (Senior manager).

Senior managers emphasised that a clear, written, regionally agreed policy on the extent of the role of various social work teams would be helpful:

> 'What would probably help everybody is if we did have a protocol where at least we had a framework for discussing who's the right person to deal with this, who's got the skill, who's got the capacity? I think regionally that seems to be a very common issue… who holds the baby literally?' (Senior manager).

Social workers and senior managers also emphasised the importance of the principle of disabled children being recognised as children first:

> 'Some tensions exist across the piece about who owns the child, and we're a long way off resolving all of those issues… where should they be? And really they should all be children first and not disability first.' (Senior manager).

Similarly, managers were concerned about the need for a skill and resource mix across disability and LAC services:

> 'My general issue is about resources and skill base. Both social work disability and LAC bring different skills experience and knowledge... children's disability are not skilled, not trained and not resourced to take on that statutory function but that's not to say if those were put in place that they couldn't take it on...

and family intervention of LAC staff would have a feeling 'well I don't have the expertise in disability' (Senior manager).

3.8.7 Multi-disciplinary Working

Social workers also worked with a wide range of other professionals in both the statutory and voluntary sectors from: health services (speech and language, paediatricians, dieticians, nursing staff, occupational therapy, psychology, psychiatry, behaviour nurse therapists, mental health, general practitioners); education services (educational psychology, private tutors, schools, classroom assistants, teachers, principals); social care services (domiciliary support, respite services); and social services (therapeutic LAC services). Good working relationships facilitated through careful planning, review and ongoing liaison and information sharing were vital, as outlined below:

> *'The only way to work with these kids is multi-disciplinary... you need to be working very closely with behavioural, psychologists, psychiatrist and have a whole team approach... to assessing the family and the child's needs… in all my cases that have worked the best they have had a really strong multi-disciplinary approach to them so for me that's probably the best practice'* (Social worker).

Similarly, senior managers emphasised the importance of multi-disciplinary working to support disabled looked after children:

> *'It's got to be multi-disciplinary… because a child doesn't function in isolation so health professionals, educational professionals and social work… all just bring a completely different dimension to it... we really need a skills mix… it absolutely fundamentally cannot be a social work team on its own any more'* (Senior manager).

Some specific examples of effective shared working were described by social workers. For example, some Trusts had formal systems for sharing information about looked after children with schools and others had developed integrated multi-disciplinary teams. Senior managers and social workers also indicated that child protection and LAC procedures created opportunities for all professionals who work with an individual child to contribute their views and participate in decisions about their lives:

> *'It's part and parcel of the child protection and LAC procedures that there is a multidisciplinary core group… to discuss and agree a plan that takes account of everything… it's seeing it that the child is part of a whole continuum… rather than seeing them all as separate sectors'* (Senior manager).

Whilst such focused multi-disciplinary efforts were highlighted as best practice for complex cases and core decisions about a child's care, some respondents

suggested that in the aftermath of such concerted efforts around particular issues, due to service structures and resource constraints, professionals often retreated back to their own disciplinary boundaries, as one senior manager explained:

> *'It probably works best when it's centred around difficult situations and then people put their energy into that... then when you've resolved that issue everybody goes back to their stations in a way… I think there's a resource issue and also probably structural you would probably need to set the whole children's services up differently'* (Senior manager).

However, there was a general view that working across professional teams depended on the effort and skill of individual professionals, as one senior manager explained:

> *'Personality comes into this as well... If you're insular and think 'well I don't know why I'm doing this', all the training in the world doesn't change that… we hide behind our roles… I think as we move into more multi-d teams maybe co-located and nurses managing social workers and social workers managing nurses… an awful lot of those discussions have got to be had…'* (Senior manager).

Indeed, some senior managers indicated that multi-disciplinary working was hindered by profession-specific policies and systems which could only be addressed at a higher policy level:

> *'Pathways are so well established for each individual discipline... the problem is they're parallel and we're really struggling to incorporate them... every discipline has their regional guidelines to follow… we feel there is a bit of duplication but when you go to look at which bits can you leave behind, it's none of them because each professional head will say I'm not allowed to say we're not doing this, this is a regional guideline… we're trying to get single documentation… and it's really difficult… rather than trying to make it on the ground we need to go back up to department level and say look here is all these assessments… they're all being done to families… are they all required?'* (Senior manager).

3.9 Access to Specialist Services

All disabled, looked after children have a named statutory social worker from 'looked after child' (LAC) services who have statutory corporate parenting duties with respect to children in the care system. However, disabled looked after children may also present with mental health needs requiring input from tiered 'child and adolescent mental health services' (CAMHS) including community based support and outpatient or inpatient services involving contact with a range of mental health specialists including psychiatry, psychology and counselling. Disabled children may also require access to children's disability services including family support services, short

breaks, summer activities and transition support. A range of professionals associated with children's disability services could be involved, including social workers, community learning disability nurses, psychiatrist, clinical psychologists, specialist medical professionals, physiotherapists or occupational therapists.

Generally, there were high eligibility thresholds for access to children's disability and mental health services. For example, some children with undiagnosed, borderline or mild levels of impairment did not meet eligibility requirements for children's disability services and children with an intellectual disability often did not have access CAMHS. Issues relating to access to specialist services were commonly highlighted by parents, carers and social workers. In the context of increasing emphasis on efficiency savings and resource constraints, tight eligibility criteria were being used across services resulting in longer waiting lists, reduced access to specialist support and increasing pressure on LAC teams as the main service provider for disabled, looked after children and young people, as highlighted in the following interview excerpts from social workers:

> *'Definitely there's gaps... we don't have enough support...there is unmet need everywhere... Some families don't get very much at all, you know, it's very, very limited... that's just a gap everybody's experiencing with resources that we have available to us…'* (Social worker).

> *'The current … cuts and the austerity... is just… making things so much more difficult… We have to be very firm. 'We've no money' that's our party line...'* (Social worker).

Some senior managers noted that there were no specific childhood disability policies guiding access to children's disability services. As a result, there was variation in the arrangement of services across and within Trusts, including eligibility for accessing children's disability services. Given the resource constraints highlighted, senior managers indicated that services had become increasingly specialist and fragmented:

> *'All services, everywhere, have specialised... so you have got to find the box that you're going to fit into... and it's very difficult because that tends to be symptom by symptom by symptom, which is the really wrong way of working with a family who have issues, dealing with it bit by bit by bit... that is a major issue because under the duty of care I think Trusts do have to have some plan for people who simply don't fit'* (Senior manager).

Within this context of high thresholds for access to services and reduced resources, this section of the report presents the study findings in disability, mental health and leaving care services, concluding with discussion of some of the voluntary sector services children accessed.

3.9.1 Disability Services

Disabled children and their families were engaged with a range of disability services, from those focused on diagnosis, to short break services and therapeutic support. Most who did have access to children's disability services were positive about the type of supports they have received. For example, one parent appreciated the individual support provided by a befriender for her son:

> *'He has a befriender, he's lovely. He lifts him after school and takes him out and leaves him back... but you only get them for so long'* (Birth mother).

Another mother described support they received from behaviour teams in managing a particular aspect of their son's care:

> *'He did have a lot of problems before toileting and soiling and that's worked itself out. That's a huge, huge difference... The behavioural team did a lot of work with him over that. They were great... they worked with visual supports and social stories... his was more anxiety linked and once the anxiety was sort of worked on that sort of stopped'* (Birth mother).

Short Breaks

Short breaks were a key source of support from children's disability services highlighted by birth parents, carers and social workers. These could involve overnight stays away from the family home in residential or family-based care, practical support within the family home or daytime social opportunities for the child. Short break services were also used to support foster placements or the return of disabled children back home to their birth parents.

Foster carers and birth parents reported that children enjoyed short breaks and it gave them time to have a break and spend with their other children. One child however, reported finding the experience of going to short breaks quite stressful. He became upset during his interview as he had an imminent short break stay and it was clearly on his mind. He kept repeating words that had clearly been said to him:

> *'No tears, no tears, no tears, no tears, no tears, not worried... nothing to be afraid of'* (Connan).

Although he tried to reassure himself that he would only be away from his birth parent for a couple of days, he later broke down saying:

> *'I don't want to go to....I miss my mummy'* (Connan).

Whilst it was clearly apparent that this young person did not like going to the short break unit, from this child's mother's viewpoint the short break support he availed of had prevented his relinquishment back into care. However, an alternative, family

based short break service may have been a more appropriate solution for this child who found group short break setting particularly difficult.

As short breaks should also meet the needs of the disabled child, social workers highlighted the importance of making a good assessment to secure the right type of short break support:

> 'Families need to have a really good assessment... sometimes we get lost within the child's needs and the parent's needs because at the end of the day they're all interrelated... it's not just a matter of just having them out for the sake of it, it's actually having tailored somewhere where they can enjoy' (Social worker).

Social workers indicated that longer periods of overnight short break stays would only usually be offered when all other short-term supports had been provided and there were still ongoing support needs. Despite this stepped approach to short break use, social workers were concerned that need for short breaks far exceeded the availability of such services. Sourcing short breaks for carers of disabled children with multiple and complex needs could also be challenging. For example, one social worker explained that accessing short breaks for those caring for disabled children with challenging behaviours or complex needs was difficult because residential short break staff were not trained to address their needs.

Direct Payments

Some social workers were aware that support that could be provided via direct payments, however, others highlighted a lack of knowledge about how to set up direct payments and indicated that training was needed:

> 'We wouldn't have the first clue how to set up direct payments. So how can we help our parents or carers to access services and resources... when we don't really know about it, you know?' (Social worker).

In other cases social workers did know how to process direct payments but found that it could be difficult to source someone to provide the support funded by these payments:

> 'We got somebody direct payments recently and they couldn't find somebody to work with their child' (Social worker).

Other social workers highlighted the flexibility of using direct payments, as one social worker explained:

> 'In one case a child's granny is doing the direct payment for the child so she's offering respite and she'll come to the child's home and look after the child. Now financially she couldn't have done it but because we're able to pay her,

she can… So direct payments has definitely been very good because the parent trusts obviously the grandparent' (Social worker).

Similarly, a senior manager explained the benefits of direct payments:

'Direct payments have been a tremendous boost and support because it has allowed flexibility for parental and carer support that was never there before... it helped keep people below the threshold in terms of breakdown' (Senior manager).

Eligibility for Children's Disability Services

Access any of these short break services or direct payments, disabled children and their carers first had to be eligible for disability services. Overall, there were challenges with access to children's disability services including varying eligibility criteria across Trusts, waiting lists for some services and delays due to lack of diagnosis.

Although there has been policy direction away from use of an IQ measurement to determine access to disability services, it was clear that most Trusts still used this approach and, the more severe the level of a child's impairment, the higher likelihood of accessing children's disability services.

'We get very caught up in the whole issue of whether or not each child falls into that severe learning disability category because their IQ is below a certain number... I get a bit worried about that, you can't take it just based on a child's IQ... we definitely need a whole clinical assessment... because children will obviously function better at different things... I don't find the whole IQ issue helpful, although that tends to be the criteria teams... most use' (Senior manager).

'We don't use the term severe learning disability but in real terms that's what we mean... significant impairment of cognitive and social functioning and so the criteria is reasonably high within the disability world' (Senior manager).

When disabled children did not meet the criteria for access to children's disability services, the onus was on the LAC team to provide services to meet their needs. However, staff in LAC teams indicated that they did not have specialist skills for working with disabled children and lacked knowledge of, and access to, additional support services for disabled children:

'If you have a child who is at the top end of moderate and just falls below severe... they're not able to get the kind of service that's helpful... through the disability service, because again the LAC teams don't know what's available out there or how to access it... they're not able to access the behavioural support teams for example' (Senior manager).

There was some frustration among social workers about some of the blanket exclusions of some disabled children and young people from children's disability services, as one social worker explained:

> *'Children with a moderate learning disability can't access the disability team. They don't meet the criteria. I don't think that's fair at all. I'm sure they're missing out on a lot of support and different services. And the foster carers especially are probably missing out on a lot of guidance and advice and support as well. I don't think that's good enough'* (Senior manager).

However, some Trusts had more open policies and accepted disabled children who were not yet diagnosed or who had moderate levels of impairment but higher levels of support needs for their families. These children were recognised as 'children in need' and were receiving family support services under the Children (NI) Order 1995, as one senior manager explained:

> *'The threshold is very low because we're operating under the Children Order, so we don't have an IQ level... actually most children with a disability will be in our service…'* (Senior manager).

> *'Certainly adult services would still be referring to the social adaptive functioning report... whereas for children's services that is not the situation, we have been working with many children who don't have a clear diagnosis but... we look at the need and then we respond to that'* (Senior manager).

There was some concern about the growing number of children with more complex health care needs or life limiting conditions and the increase in children presenting with ASD. These population trends were placing additional pressures on already over-stretched children's disability services. Looked after children with ASD could access support from ASD services or the LAC team. If children with ASD also have an intellectual disability they may or may not be able to access support from the children's disability service, as these senior managers explained:

> *'We don't exclude children with autism... we have a part time social worker who works with families of children with autism and their families, so you can imagine that the capacity is very, very limited there'* (Senior manager).

> *'You have to have a severe learning disability range so an IQ of around 54... so we tend not to work with kids with ASD or moderate or mild learning disabilities... that's a threshold, gate keeping issue, we just haven't got the resource to do everything'* (Senior manager).

However, as one senior manager explained, the onus should be on a robust assessment of need and allocation to the team best placed to meet that need:

> *'I would like to see a holistic assessment done that clearly looks at need, not IQ, and if the need falls within the remit of a team then that's their team. I have seen a child miss out because a psychologist very strongly and ethically*

has said I do not wish this child to be labelled. I totally get that point however by not labelling them they didn't get any services' (Senior manager).

Transition from Child to Adult Disability Services

In addition, there were concerns about the transition to adult services. As some of the young people involved in the study were aged 14-16 years, there was some discussion of the challenges of transition to adult disability services which has higher eligibility criteria and reduced levels of support for disabled young people and their carers:

'Transition services for the moderate ones are weaker than the ones with the severe learning disability because adult services won't take them, so that is the difficulty and then the 16+ teams are trying to manage them up until 22 or 23, depending on need... getting a case moved across to adult services can be quite difficult' (Senior manager).

One parent discussed her son's upcoming transition from child to adult disability services and the limited work undertaken to develop a transition plan:

'We don't know because it hasn't really been talked about. The social worker hasn't really done an awful lot as far as the future's concerned. There's no transition plan or anything started yet. Where he'll be living or anything like that, we don't know... I don't know how he's going to support himself... I don't think he ever will be able to live on his own... As far as planning for the future, nothing's been done yet' (Birth mother).

In relation to the transition to the adult service, social workers highlighted the need for early planning and engagement with adult services:

'The problem is that the adult team so far have not properly dovetailed with us. They need to be joint working with us from the age of 17. The problem is that they don't seem to... very, very rarely do we get anybody from their services… in fact it's the opposite. We're trying to hand over a baton to someone who's sprinting far away from us as quickly as possible' (Social worker).

The high cost of care packages in place to support disabled children were emphasised as being a critical aspect of discussions with adult services, as the following comments from senior managers illustrate:

'There's always going to be interfaces with transition... because some of these children need very high cost packages... then it's trying to get the adult services to buy that and that normally does not happen... so there's definitely gaps in the service... we don't always get that   right' (Senior manager).

'Adult services are finding it difficult to find the dosh that they need to provide to provide the supported accommodation that these young people will have to have, so finance, is a huge issue... we project, we tell them, we invite them to the LAC reviews of those children who will require permanent accommodation, so they know from 16 onwards... adult services have that information but when it comes to coming up with a plan for 18, money is definitely the issue, because adult services used to say these are LAC so there's a squad of money tied in with them and surely that money should come across with them but actually... there's not a lot of leaving and aftercare money' (Senior manager).

Due to these difficulties related to transition from child to adult disability services, some Trusts had developed systems to engage with adult services to facilitate early planning to meet the needs of the population of disabled children due to transition:

'It requires both children's and adult's to come together... last year we had a higher than normal amount of children transitioning... so we decided to have a workshop with adults to sit down and plan who's coming through, what their needs are, what the high cost might be, who could meet that need and we invited providers to that so providers were able to do a match to what they could provide and what the children's needs were. That worked to a point but some of the children they require business cases... so it's not easy' (Senior manager).

There was, however, still a general view that adult disability services did not have resources required to meet the complex and multiple needs of the adult population and there were major gaps in provision, as the following senior managers explained:

'The adult learning disability system is creaking... there are massive resource issues for them and these placements can be extremely expensive, we've had dog fights over the money that pays for the placement going to adults... which has influenced relationships and not in a positive way... it's the most challenging issue and interface that we have and it's not getting any better despite repeated efforts... resources are a big part of it, attitudes are a big part of it too but... families find it a very disjointed process, they are unhappy with transition processes into learning disability services in particular... and then families of children with autism are just beside themselves because if they're very lucky they'll get something from mental health and very often nothing, so you know for me the biggest issues are not the 16+ transition service it's adult services' (Senior manager).

3.9.2 Mental Health Services

Looked after children with low level mental health needs accessed mainstream community based supports or LAC specialist therapeutic services. For those with higher level mental health needs, specialist CAMHS were often sought. A range of

professionals were involved in the delivery of these tiered services including psychiatrists, psychologists, nurses and counsellors. Some of the participants in the case studies were engaged with mental health services and described their experiences. For example, one young person recalled how she had not found counselling to be of any help:

> *'I've been to counselling, I've been to anger management, but I've never really liked it because I suppose I don't really understand what they're talking about and it's so much stress and people telling you do this and try that... plus nearly every way you can think of to cope with your anger I would have tried already'* (Shauna).

For some young people, mental health needs only became apparent during their time in care. Deterioration in mental health could be linked to earlier experiences of abuse or neglect, separation from birth family or difficulties associated with their care placement. One mother talked of how some of her child's difficulties became more pronounced when she became looked after and how services failed to meet her child's mental health needs:

> *'She never self-harmed until she went into care... I spoke to the psychologist and he was actually near crying with me because it just felt like, to me as a mummy, it felt like I was just throwing my child to the wolves...'* (Birth mother).

One parent also expressed concern about the lack of professional support for her child, particularly at weekends when services were reduced and crises often emerged. This mother talked about her child's fragile mental health in the absence of adequate professional support:

> *'The weekends were horrific. She'd phone the police after cutting... or she'd say to me "Take me to hospital, my mental health's away"... and we'd get to hospital. We'd stay all night and they'd say "you're her place of safety. Take her back home". So we'd go back home'* (Birth mother).

Whilst another mother spoke equally negatively about the mental health support available to her child, she acknowledged the pressures on the mental health service staff who were working with her daughter:

> *'It's terrible... even whenever she was at hospital she had a social worker... and he had a whole ward full of people to look after and it's just like putting a sticking plaster over... a chopped off arm. And you could just tell the guy just had so much to do. He rang me like a month after she got out said 'I just got a message from you' and I said 'I left you that a month ago'. But you could tell he was trying, you know'* (Birth mother).

Another parent highlighted the importance of a good working relationship with those providing therapeutic support:

'She had a good relationship with the social worker with TSS but he actually left... She's actually a good relationship with X (clinical psychologist) too and I would be able to go and speak to him if I had problems or worries about her' (Birth mother).

Eligibility for CAMHS and LAC Specialist Therapeutic Services

Social workers placed an emphasis on strong multi-disciplinary relationships when assessing, planning, intervening and reviewing the emotional and mental health needs of disabled children. For children who had accessed CAMHS, social workers spoke highly of this service. However, social workers were concerned about delays in accessing mental health services and expressed some frustration for disabled children who could not access CAMHS, as one social worker explained:

'Access to CAMHS has always been very difficult because they tend not to work with children with disabilities… they are just seen in terms of their disability as opposed to the many other things in their lives that makes their life difficult. You know in some cases for a child, disability has been the least of their problems. They are much more impacted by their family situation by things like domestic violence and abuse… poor parental mental health so sometimes I feel that you know it's a cop out for other agencies to say 'oh no, disability services should be dealing with that' when in fact they're the ones that are best trained to look at that... say violence or early childhood trauma. And you know it's just frustrating, you know, really frustrating' (Social worker).

Senior managers also reflected concerns about lack of access to CAMHS for disabled children and young people, including those in the care system who are likely to require specialist mental health services:

'There definitely needs to be better links with CAMHS.... in some cases CAMHS won't accept a referral from a child with an intellectual disability... they would say there are issues around capacity to engage in their services and that they don't have the expertise to deal with children with significant learning disability... And it tends to be a very clinical model that doesn't work with children with disabilities so well because families may need somebody to come to them' (Senior manager).

The same theme applied to LAC specialist therapeutic services which were much valued but withdrew when CAMHS or behavioural support teams became involved:

'Our LAC specialist therapeutic service have been very good and... they are happy to work with the ones with a mild to moderate disability but if… CAMHS have to be involved at any level, they'll step back so all of these services will do so much and go so far and then they will back out' (Senior manager).

Senior managers also explained that CAMHS were crisis led rather than responsive to the ongoing mental health needs of looked after children and focused on a clinical, medical model approach to service delivery:

'I have a concern about how CAMHS are accessed... as demand has increased, the threshold has just become higher and higher... it's fine if we have an acute episode... we will get that immediate crisis response but after that it's almost like they don't have a mental health problem... some of it maybe is the difference between the social care model and the medical model, you're either sick or you're not sick' (Senior manager).

'It probably needs changed from being strictly a CAMHS medical model of your diagnosis or particular mental illness or disorder... there are very challenging and particular needs that come from being an extremely traumatised looked after child ' (Senior manager).

Another senior manager indicated that low use of CAMHS for looked after children could reflect a reluctance to stigmatise children further with another label:

'The other thing that's around for LAC social workers is the whole idea of not putting another label on a looked after child, you know, the idea that the child already has a significant trauma to deal with throughout their childhood and into their adult life by virtue of being looked after... so it's you almost have to fit them into a wee box to get those services but not wanting to put another label on the child' (Senior manager).

Without access to CAMHS, looked after children and young people with intellectual disabilities had to rely on psychiatric or psychological input from learning disability services, as the following senior manager explained:

'We have a very vulnerable girl who's on the CSE register, she has a few learning disabilities, goes to special school, but it's a learning disability clinical psychologist who's involved with her from a therapeutic point of view... as a looked after child she should really have access to therapeutic LAC' (Senior manager).

However, there were some concerns that mental health support from a learning disability service could have a different approach and could lead to a narrow focus on medication rather than broader therapeutic support:

'Sometimes the mental health need is masked by the disability and it's put down to challenging behaviour and not seen as an expression of distress and sometimes I wonder whether or not the prescription route is more quickly availed of for children with intellectual disabilities who will more quickly get medication rather than talking therapy or therapeutic work that might help to resolve some of the things that are causing the pain' (Senior manager).

In response to some of these concerns, one Trust had sought to develop a targeted CAMHS for children and young people with intellectual disabilities.

> *'We are moving towards a CAMHS LD model that we are piloting with a single point of entry and... a home assessment and treatment team which is really about very, very high intensive support at home to prevent hospital admission… tier 3 and tier 4... as we have moved forward in the CAMHS LD model we become more knowledgeable about the nature of the presentations... the impact of mental illness and also the damage of neglect and of these young people not having their needs met because they haven't been understood... when you have the specialist teams in place you get a clearer picture'* (Senior manager).

There were similar challenges for the transfer from CAMHS to adult mental health services (AMHS). Delays in assessment and higher thresholds for access to AMHS were commonly highlighted. In addition, a more clinical approach to AMHS created a shift in the culture of the service for young people with mental health needs and the closure of cases if initial appointments were not attended meant that some young people were quickly excluded from AMHS. Given these concerns, some social workers indicated that CAMHS sometimes offered more flexibility and stayed involved during the transition period, as one social worker explained:

> *'There was one very complicated case... and they held on to it well beyond what they should have done and took an interest in that young person... but they were very easy to work with around that case so... there's a wee bit of flexibility there'* (Social worker).

3.9.3 Leaving Care Services

Several case study participants were engaged in preparations for leaving care, which brought both fears and expectations, as one young person stated:

> *'I'm like very scared I suppose, but I just want out of here I want to actually have the independence that I should have at my age... I want to have control over my own life and not have people telling me what I can't do... I want to do it myself so I do want to leave. But in a way I'll probably miss some of the support I have'* (Shauna).

Others were uncertain about the transition process and options seemed more distant, although the young person clearly felt that he would have a say about his future:

> *'…you can stay here 'til your 19 but then you really have to move on but they can't decide for you. They can give you a few options like the social workers, but the young person has the most say what he would like and what he wants'* (Adam).

Across Trusts, there was some variability in ownership of cases as disabled looked after children turned 16 and began preparing to leave care. In one Trust, all cases transferred to 16+ services. However, in most cases, these young people remained with the children's disability team if they were known to those services, as one social worker explained:

> 'They would generally stay with disability services if we had been working with them for any length of time... to try to keep that continuity particularly at that difficult time because it's a very scary time for the children' (Social worker).

With such approaches, children's disability teams held full responsibility for the case and called for greater engagement from adult services:

> 'For those disabled children, who are transitioning through into adulthood, the personal advisor role is fulfilled by their children's disability social worker... just because their social worker has more of that specialist and skilled knowledge about their ongoing day care or residential units.... That doesn't really pose any particular problems because they still have access to the 16+ team for advice and guidance... but it's not straight forward... we have talked about developing a 16+ team for children with disabilities but that will require a buy in from adults really to make that work' (Senior manager).

However, there was no clear consensus on whether this approach was appropriate to meet the needs of disabled care leavers, as illustrated in the following quote:

> 'Recently in the transfer of a young person from the LAC team due to go to 16+ services because of her age, the feeling from 16+ was that they would provide the PA and independence training... but they wanted the social work end to sit with the children's disability team who were already co-working and that raised a whole lot of interface issues so there's potential for a whole lot of work there' (Senior manager).

Overall, there appeared to be a lack of consistency across Trusts in terms of who held responsibility for disabled care leaver cases, as the following quote from a senior manager demonstrates:

> 'Our experience of it is patchy. The ones who have been in the LAC world do get referred to 16+... we will co-work and advise about placement options... but we're not carrying the whole case... We can't get personal advisors for love nor money. I am told that's because there aren't very many of them and those that they have don't have the expertise... we do make a point of getting access for all our care leavers to leaving care grants and the GEM scheme for people who have been in foster care and could transfer to an adult placement' (Senior manager).

> 'Those who have the severe learning disabilities, challenging behaviour, they don't transfer to 16+ we just hold on to those and carry them right through until 18 and subsequent transfer to adult services, because

those are young people who require permanent beds... a home from home for life, they'll not be returning to parental care, so we retain those youngsters... very few go to 16+' (Senior manager).

For young people not already engaged in disability services, transitioning from LAC services meant a referral to 16+ teams and/or, perhaps later, a referral to adult disability services. Those with mental health needs moved on to 16+ services and, if required, referrals were also made to transfer to adult mental health services. Given the varying pathways to adult life with engagement across service domains, one senior manager urged the commissioner of services to clarify the resource allocation stream for disabled care leavers:

'Not all resources come down the one line, some will come to disability, some will come to LAC, some will come to GEM scheme... I think the Commissioner needs to be a bit more firm and clear when funding comes down... there's no explicit, who is this about, we're assuming it's for all children... it's really not clear and I think that that needs to be done so that there is a more equitable approach, and if there's schemes developed regionally for children leaving care they shouldn't forget about disabled children who have been in long term care' (Senior manager).

Some social workers reported struggling to implement plans for young disabled person transitioning from care due to the lack of available supported living placements. They also highlighted the need for a phased transition approach, where relationships with new staff are established prior to moving in order to maximise the chances of the transition going smoothly:

'If we can… we do it in as much of a phased way as we can... it's crucial that cross-over because that's really where it can all go wrong... whenever a bed becomes available, then the staff team start an assessment with a young person, they would meet with them and start to develop those relationships' (Social worker).

Social workers in 16+ services were concerned that some young people could disengage too early from adult services and move into adult life without adequate support:

'He already has crossed over to adult mental health services but... he's just finding that…difficult so at the minute he's really backing off. He's not engaging with this new team... so that would always be a concern for us that just some young people turn 21, you know, they're just not ready to not have that support' (Social worker).

The need for a flexible 16+ service design was highlighted based on the centrality of relationship with disabled young people and an open door for those who wanted to come back for informal advice as they move into their adult life:

'There are some young people who just cannot manage their life sometimes… you're thinking 'No I really don't want to close them. I really would like to stay involved'… we would have young people who would come in, you know, months, years after they've closed... obviously you're not going to be able to do practical things but you can kind of signpost and give advice and direction... you've even ones that come back with their kids, you know, it's nice' (Social worker).

In the context of the challenges of supporting the transition from care for disabled looked after children, several Trusts were in the process of developing new ways of working. In one Trust 16+ service managers chaired LAC reviews when young people in care reached their 16th birthday. In another Trust a written transition guide for those working with disabled care leavers was implemented to guide transition planning with clear roles and responsibilities of various agencies specified, however, there was some concern about the extent of its successful implementation:

'We developed a good practice guidance for transitioning of LAC disabled children... we are very proud of it... it very well sets out all of the roles and responsibilities in terms of transition and that's goes right across all professional groups and all agencies... I would love to be assured that is has led to a really integrated approach to supporting those young people in making transitions to adulthood... yet I can't say that it is because there still seems to be deficits in terms of collaboration and opportunity... adult services have not been resourced to the point that they need to be....I don't think we have got it right yet' (Senior manager).

3.9.4 Voluntary Sector Services

Some young people and their families talked about their engagement with a range of voluntary sector services, including VOYPIC, NIACRO and MACs. Some young people had positive experiences of these services, however, it seemed that in the later teenage years young people grew out of their engagement with the services, as one young person stated:

'I used to be in contact with VOYPIC but then sort of grew out of the idea' (Shauna).

Another young person explained that, although she had become aware of various organisations set up to support care leavers, she did not anticipate accessing support from these organisations because they would be reminders of her life in care:

'Yeah there's a few different organisations that helps care leavers like MACS... I only found out about this year that does a lot of work with care leavers... I don't go to MACs, I don't like the idea of it. It's too much like a care sentence too big' (Shauna).

One young person explained how she had felt let down by a volunteers with whom she had had contact but which ended abruptly without warning, she reported:

'Yeah they were good but the girl from NIACRO just got up and moved and then the girl from VOYPIC just left and didn't come back one day and didn't contact me again...The VOYPIC was when I was like ten and I really liked the girl and then it just annoyed me' (Shauna).

Some parents talked about support they had received from Woman's Aid. For example, one parents explained how Woman's Aid had been a significant support assisting her to take steps to regain control over her life and have her children returned to her care.

Social workers mentioned a number of services they connected with including Positive Futures, Home start, Sure start, NSPCC, Barnardo's and Autism NI. Social workers were very positive about voluntary sector services on offer, including their flexibility, as indicated below:

'Home Start are an absolutely brilliant organisation and Sure Start as well... always kind of looking outside the box' (Senior manager).

Furthermore, it was the social workers' view that the voluntary sector makes good use of its volunteers for the benefit of disabled children as highlighted below:

'The thing with Positive Futures is the leaders in charge are very good at drawing up a very good plan so that they can then tell their volunteers 'well this is what works for him'... and keeps the kids entertained but also content... and that again helps the parents then because they know their child's having a good time and for them it's a real social activity... knowing their child is away off playing with their friends' (Social worker).

Social workers also highlighted that the voluntary sector sometimes offers additional services not always available in the Trust including training. For example, one social worker had accessed training on ASD issues relevant to her caseload from Autism Initiatives and Autism NI.

3.10 Unmet Need

Social workers were acutely aware of the range of unmet need for disabled children and young people and their families. Earlier sections of this report have identified major gaps in the availability of short breaks, therapeutic support for disabled children who have experienced abuse or neglect, alternative care placements within jurisdiction and community based interventions. These points were also evident in interviews with senior managers as the following comments illustrate:

> *'It's early intervention... talking therapies and community home treatment models... that would really help for children with autism and behavioural problems'* (Senior manager).

There were also unmet needs highlighted for particular sub-groups of disabled children and young people, including those with ASD:

> *'I think the Autism Act may have clearly defined the population of those with autism and given them a very clear identity as children in need... but I'm not sure that it did anything more than that... what has happened is that children with disability services... have ended up with the responsibility... without any additional resources... so the unmet need is largely around early intervention'* (Senior manager).

Indeed, one senior manager indicated that the extent of unmet need could be hugely under-estimated as expectations of disabled children and their families have been lowered:

> *'It's massive... a lot of the unmet need that we would know about is masked because either people don't even ask anymore because it's not there or because they're steered away from certain things towards what's available'* (Senior manager).

In addition, senior managers with considerable experience of managing services reflected on the increasing demands on services as higher numbers of younger children presenting with more complex needs impact on the system.

> *'There is a cohort of children that I'm really struggling with and that's the children with complex physical healthcare needs... really high level... 10 years ago these children wouldn't be alive... the numbers are small enough across the five Trusts to justify some form of regional provision for that cohort of children who present with very severe learning disability, severally challenging behaviour'* (Senior manager).

The impact of resource constraints and efficiency savings also raised concern about the extent to which existing services could be maintained:

> *'I have great concerns around unmet need... we are squeezing and squeezing our resources... we have a menu of short break support and there is a challenge to maintain that and to develop innovative ways to support disabled children'* (Senior manager).

There was also a sense that some services had become reactive and crisis driven, rather than focusing on early intervention, as one senior manager explained in relation to behavioural support:

'At the lower end of need I feel we have insufficient early engagement with behaviour support... we probably are addressing behaviour as a crisis rather than going in earlier and trying to prevent the crisis' (Senior manager).

Some respondents indicated that a stepped care model with more intensive support for families who were struggling to maintain their caring role would help to prevent admission to care:

'We do have these children who need intensive support. We can see the parents are reaching breaking point, crisis point... so we want to develop a stepped care model approach, whereby we can offer a 24/7 intensive support service to families… to reduce the need for an urgent admission… and that high level, crisis response.... There's a big gap there' (Senior manager).

In addition to more specialist family-based and residential services, most senior managers also emphasised the importance of building community-based, early intervention services:

'The fundamental problem is we haven't equipped our communities to provide the sort of tier 1 tier 2 services... quite often an early response by community workers would be more appropriate at an earlier stage but there is nobody there to do it then the situation builds... then suddenly it's a social work crisis... when it reaches a social work door very often it is too late... they wait til they are a priority by which stage they are in crisis... if we provide services in the community helping them prevent reaching that stage, we won't have as many come through the system and our pressures will ease... but unfortunately we have not got there yet.... and cuts to preventative service saves up problems for later on' (Senior managers).

3.11 Good Practice

Whilst the case studies clearly identified areas for improvement in services for disabled looked after children and young people, there were also examples of good practice across Trusts. At the individual level, children, parents and carers positively appraised individual social workers. Indeed, at the time of interviewing, one social worker had been nominated by foster carers as social worker of the year as part of the NI Social Care Council awards.

At a wider structural level, innovative approaches to practice had been developed in response to concerns about inadequate provision or the increasing needs of the population. For example, as discussed earlier, one Trust was developing a CAMHS learning disability service including a single point of entry to trans-disciplinary, preventive mental health services. In two other Trusts, dedicated posts were created to focus on the needs of children with autism and their families. In another Trust specific strategies were in place to connect the disability and fostering teams in an

effort to secure more suitable fostering placements for disabled children and young people:

> *'We now have regular meetings with the disability team that we didn't have before where they're flagging up children who need fostering at an earlier point and we're then doing campaigns and programmes to try and get foster parents for these children and that has been quite successful. We've managed to foster quite a number... including high end cases… having the cases flagged up well in advance to give us time to identify people has certainly been of benefit'* (Senior manager).

Staff in all Trusts emphasised the importance of early intervention, family support and shared care approaches to support parenting capacity and prevent full-time admission to care. Parents and carers who had access to short breaks very much valued this support. Similarly, senior managers indicated that short break and shared care placements with highly skilled and experienced carers were examples of good practice:

> *'Our short break and respite arrangements are actually helping families be families... an awful lot of the carers are folk who have a familiarity with children with disability... so they don't have a fear of the disability per se and can see the child for the child... some arrangements start when the child is very young and the carers actually transition across to adult services with the child who becomes 18 or 19'* (Senior manager).

Joint working with a range of professionals across disability, mental health and LAC teams were also important features of effective practice. For example, one social worker emphasised the importance of good working relationships across social work teams and other related agencies:

> *'A positive for us is all those agencies we've worked with for many years and there's good working relationships there and you get to know quite quickly what ones would fit with certain young people so you can almost cut out a bit of the wasted time sometimes, so that does work well... it's always been that very focused knowledge skill base around our particular type of client group'* (Social worker).

Another social worker identified multi-disciplinary, partnership-based approaches to working with children and parents as best practice:

> *'One of the best pieces of practice is when you have... constant multi-disciplinary working... and we're not all so precious about our own roles... sharing our information, sharing our resources and pulling together to help the family... when we do that it is much more beneficial. I mean getting Mum, everybody involved not just professionals... really building that relationship with a family is vital... then you're a resource for that family'* (Social worker).

As some disabled children and young people with borderline or mild to moderate levels of impairment did not meet the criteria for children's disability services, mainstream LAC teams and 16+ teams also undertook additional work to support these children and young people. These efforts to provide consistent support for these disabled children and young people were noted by study participants and were also well supported by other statutory and voluntary sector providers, as one senior manager explained:

> *'Some of the young people on the borderline... through our supported accommodation we get to offer a closer level of support at least up to 21... and often we will engage with housing executive around long term floating support services... the housing executive will be very flexible with us... and with those local providers of those supported accommodation facilities for example, Praxis... that has also made it easier to work with that borderline group and... even though they are not diagnosed as such, their expertise supports those young people'* (Senior manager).

Overall, staff were positive about the transition guidance for disabled children and young people leaving care in one Trust area. Unfortunately, this was not being implemented regionally and did not have a significant impact on the availability of adult services, however, it did assist professionals in their transition planning. One senior manager explained the benefits and continuing challenges for implementing the transition guidance:

> *'The guidance does keep people in track with what they have to do... we are able to agree the plan for a young person post 18 but the key issue guidance never addresses is the adult support issues and young people still move into learning disability residential homes at 18... and the reason for that is simply adult services could not provide a facility to meet those needs... so the protocol is good but the services at the other end... they just don't have the resources that child care have available to them'* (Senior manager).

The need for transitions from care to be carefully planned and supported, with close engagement from child and adult services is clearly evident from the findings of the study. In one Trust, a LAC disability forum had been established and worked with transition staff to develop a person-centred transition mapping tool which had also been nominated for a regional award.

Another aspect of good practice highlighted by staff in some Trusts was engagement with service users and carers and new partnerships with the community and voluntary organisations. Such community development efforts were highly valued and had the opportunity to support social inclusion and embedded community supports. However, the senior managers cited below emphasised that such community work needed investment and recognition:

> *'Local community groups are all up for this... they are being inclusive and accessible... and some are very, very good... and get on with it and they see as well the outcomes from this are so good it's well worth the effort... and I'm*

thinking why can't people up there see that this is the way to do it... but it's not cost neutral ' (Senior manager).

'I really am very impressed with some of the work that they have done with community access... that is very important to highlight given the current funding situation... there needs to be a little bit of seed funding for volunteers... they do need training, monitoring, checking, reassuring, thanking, all those things, and it takes money to do that' (Senior manager).

In one Trust, the structure and positioning of services were being re-organised to facilitate more integrated services and support hubs which were also being positively evaluated:

'We're about to co-locate all our social work nursing and psychology and behavioural services to create a hub... where our staff are co-located we can work more efficiently, we can share knowledge and practice... we have the children's interdisciplinary schools team... which takes on an early intervention role... that's an amazingly well evaluated service... the outcomes for that particular type of service are considerably better than anywhere else... it's a really good evidenced-based service' (Senior manager).

Overall, in the context of service cutbacks and resource constraints, managers reflected that staff have been working exceptionally hard at maintaining high quality services and creating new ways of working:

'I don't think that we do very badly even when you look across at other countries... I do think that there are a lot of very dedicated social workers who do a cracking job' (Senior manager).

4.0 Discussion and Recommendations

This report has presented the findings from the case study phase of the project which has produced rich data on the views and experiences of disabled children and young people in out-of-home care, and those of their parents and carers. Findings from interviews with their social workers and senior managers responsible for childhood disability and children's services also highlight pertinent issues for the provision of services to meet the needs of disabled children and young people in out-of-home care and their families.

4.1 Early intervention and preventive family support

Preventive rather than crisis driven practice is a recurrent theme with families of disabled children requiring earlier intervention and targeted support services when they are facing challenges. Whilst some parents and carers were well supported, others felt that the absence of essential support services had directly contributed to the breakdown of their family and their child's admission to care. Indeed, in some of cases, children later returned to their birth families with increased supports in place.

The importance of early diagnosis of impairment was also emphasised. Whilst there may be a need to allow time for a child's growth and development before a clear diagnosis can be given, birth parents and carers want their concerns about their child listened to and responded to with prompt assessments from relevant professionals. In some of the case studies, parents and carers made repeated efforts to have their child assessed and diagnosed and felt that their knowledge of the child's needs should have been taken into account. Without a clear diagnoses, children and young people struggled to gain access to specialist services and carers had limited access to advice or support about how best to meet their needs.

The data also indicates that there can be an increase in complexity of need and challenging behaviours as disabled children age into adolescence. Indeed, the young people availing of specialist or out-of-jurisdiction residential placements were older and had a complex range of needs and challenging behaviours that had escalated over time but had often only been diagnosed in adolescence. Parents these young people indicated that earlier diagnosis would have helped to better understand their behaviours and need for structured support and routine in their early years to prevent a deterioration in their health or behaviour and a breakdown in their family care. Early diagnosis is also important in terms of the identity of the child and their understanding of their impairment-related experiences and the context for their behaviour.

4.2 Investment in relationships and support whilst in care

Following admission to care, disabled children and young people and their parents and carers need continued support. Non-relative and kinship carers require specialist training and short breaks and other supports as they often assume long-term caring roles for disabled children. Birth parents also require ongoing support. In many cases, the impact of demanding caring roles on birth parents was apparent, often resulting in poor physical and mental health. In addition, all birth parents spoke of their experience of feelings of loss and separation when their children were taken into care on a full-time basis. Despite their own needs, birth parents were sometimes unsure who to turn to for individual support as their contact with social work often solely focused on the care and protection of their child. The positive effects of support for birth parents whose children had been taken into care were clearly evident in cases where birth parents later resumed of their disabled child when they had accessed breaks from their caring role, counselling and/or parenting skills programmes.

The narratives of disabled children and young people were also punctuated with experiences of trauma, abuse or neglect and loss. In addition, they were negotiating complex family, disability and care identities often in the context of disabling experiences of exclusion or bullying. Whilst individual social workers described some cases where they had undertaken one-to-one work with disabled children on their caseloads, few of the disabled children in our study had access to therapeutic or counselling services.

Whilst professionals highlighted procedural aspects of their practice including protocols for recording, statutory visits and formal placement reviews, disabled children and their parents/carers emphasised that the cornerstone of effective social work practice is the development of trust-based relationships. Social workers who actively engaged in building relationships with the child and their family and took time to understand the wider family context were much appreciated and created opportunities for children and carers to openly discuss their concerns and needs which led to more timely and constructive advice and support. Importantly, social work practice in these cases was described by birth parents as positive partnership-based work based on a mutual concern for the wellbeing of their children. Even when children do not return home, these positive working relationships with birth parents are important for family contact and the continued involvement of birth parents as part of their ongoing shared parental responsibility role.

4.3 Inequity in access to services, placement choice and permanence

A range of issues raised by study participants highlight the inequities in service provision for disabled children and young people. There are three main issues relating to inequities in provision: (1) limited access to specialist services; (2) reduced placement choice; and (3) fewer opportunities for permanence.

Firstly, variance in levels of service provision across Trusts reflect differences in the availability of services and eligibility criteria for access to childhood disability or mental health services across the region. Most Trusts are in the process of adopting more needs-led thresholds for access to services for disabled children, however, senior managers indicated a need for a regional review of eligibility criteria to ensure equity across the region and to improve provision for children with co-existing impairments. There is much concern about lack of access to CAMHS for those already known to children's disability services. Such silo working may reflect the context of resource constraints, however, it creates significant barriers to important specialist services including therapeutic programmes for children in care or specialist mental health care.

Secondly, as social workers report significant challenges in securing a long-term placement for disabled children, a broader range of placements is required to meet the needs of disabled children and young people entering the care system. It is particularly important to develop family-based kin of non-relative care options, given the finding that mainstream residential placements do not adequately meet the needs of disabled children due to physical inaccessibility, unpredictable group dynamics and limited disability-related experience or training. In addition, there is a lack of specialist residential placements resulting in some disabled young moving to costly out of jurisdiction placements.

Finally, there are two main issues related to routes to permanency for disabled children and young people in care. Firstly, there are concerns about multiple placements and repeated reunifications with birth family or kin, often in the context of the limited availability of alternative longer-term foster care placements. Whilst birth parents should have their needs and parenting capacity assessed, it is also important that disabled children and young people do not experience multiple transitions and repeated separations from birth family. Secondly, there is a view that some disabled children may not secure an adoptive placement due to their impairment-related needs or lack of certainty about their future health and development.

4.4 Integrated, multi-sector working

Across the case studies, participants emphasised the importance of multi-disciplinary and multi-sector working to address the complex and heterogeneous needs of disabled children in out-of-home care. Disabled children and their families need holistic assessments of need and risk, and a joined up approach to responding to identified needs. Professionals working in integrated teams and co-located in the same physical building felt they had a significant advantage in relation to the potential for multi-disciplinary working. Such cross-disciplinary practice led to more creative and efficient ways of working, in the context of resource constraints and service cutbacks. However, managers emphasised that disciplinary specific policies

and training must become more integrated to further develop multi-disciplinary working in practice.

4.5 Participation of disabled children and young people

Disabled children in out-of-home care emphasise the importance of being consulted and involved in decisions affecting their lives. There were some very good examples of disabled young people having their say about placements and birth family contact. However, in many cases, disabled children felt more excluded. Opportunities to ascertain the voice of disabled children were not always fully utilised by social workers, some of whom still relied on birth parents/carers to access children's views. Indeed, the researcher on the project was able to ascertain the views of some disabled children who were deemed by their social workers to be unlikely to be able to participate in case study interviews. This may be due to inaccurate assumptions that some disabled children cannot communicate, an over-emphasis on impairment effects or a lack of training and confidence in using alternative communication skills. It is concerning that, despite their status as looked after children and their experiences of abuse, neglect and/or separation from birth family, there was very limited availability of independent advocacy services across the region for disabled children and young people.

4.6 Recommendations

1. Earlier diagnosis and prompt multi-disciplinary responses to parental/carer concerns about their child's growth and development are essential.
2. Increased availability of short breaks for disabled children and their families is required to prevent the escalation of family crises and reduce the risk of family breakdown.
3. Social workers need build close working relationships with disabled children and their parents/carers to gain a holistic understanding of their needs and develop collaborative partnerships with families.
4. Specialist training and targeted support is required for foster carers looking after disabled children and young people.
5. Continued support should also be offered to birth parents, including counselling and specialist interventions that may enable them to re-engage in effective parenting of their children, where appropriate.
6. Therapeutic services for disabled children in out-of-home care should be expanded with more access to counselling, life story work and peer mentoring.
7. Schools should more proactively address disablist bullying and support disabled children who have experienced abusive treatment.
8. A regional review of eligibility criteria for access to children's disability and mental health services is required to ensure equity across the region and

clarify pathways to support for children with various impairment types. Services should target assessed need rather than type or level of impairment.

9. A review of the availability of foster and specialist care placements for disabled children across the region is required to scope current provision and inform investment in family-based care and, when appropriate, cost efficient specialist residential care for disabled children and young people.

10. Shared care arrangements should be further developed to offer birth parents who care for children presenting with very complex needs and challenging behaviours the opportunity to share the care of their child.

11. There is a need to undertake a regional review of adoptive pathways and placements for disabled children and young people and to promote adoption as a route to permanence for disabled children and young people.

12. Policies and procedures for assessment, care planning and service delivery need to be integrated to facilitate a shared, multi-disciplinary approach in practice.

13. Budget allocation and training should move from a uni-disciplinary focus to integrated provision and co-located teams.

14. Multi-disciplinary training on disability awareness and alternative communication should be provided for all professionals working with disabled children in out-of-home care to increase knowledge of impairment effects and participatory practice that facilitates disabled children's expression of their wishes and feelings.

15. Training is required to raise awareness of the rights of disabled children and statutory responsibilities in relation to disability discrimination and human rights law in NI.

16. There is an urgent need to develop advocacy services for disabled children and young people across the region to ensure their right to independent representation and support are upheld.

5.0 Conclusion

Given the paucity of research with disabled children in out-of-home care, these case study findings make a significant contribution to our understanding of their needs and experiences, from their own perspectives. In addition, they highlight the views of their birth parents, carers and social workers which provides further insight into their care and family contexts.

This report has presented a comprehensive picture of the core issues relating to the care and protection of disabled children and young people that can inform policy and practice in NI but will also have wider relevance to the international knowledge base on out-of-home care for disabled children. At a global level, there are major gaps in empirical research on the experiences of this population, therefore, further studies replicating this methodological approach would extend our knowledge base and offer opportunities for comparisons across jurisdictions and cultures. In addition, there are areas for further research, including studies that seek the views of other

professionals who engage with disabled children in out-of-home care such as, the judiciary, police, health and school-based professionals.

The case study findings demonstrate much evidence of good professional practice, including examples of partnerships with families and integrated working. However, the recommendations above also clearly indicate priority areas for service development and improvement which have implications for practice beyond the out-of-home care population as they highlight deeper structural and systemic issues detrimentally impacting on services for disabled children and their families. We encourage policy makers, commissioners and service providers to use the findings of this report, and the previous profiling report, to inform their future decisions about investment and improvements in services for disabled children and young people and their families.

References

Dowling, S., Kelly, B. & Winter, K. (2013) *Disabled Children and Young People who are Looked After: A Literature Review.* Belfast: OFMDFM and Queen's University Belfast. Available at: http://www.ofmdfmni.gov.uk/index/equality-and-strategy/pfg-economics-statistics/equalityresearch.htm (accessed on: 09/04/14).

Health and Social Care Board (HSCB) (2013) *Delegated Statutory Functions (Including Corporate Parenting Report) Statistical Report for September 2013.* Belfast: HSCB.

Kelly, B. (2007). Methodological issues for qualitative research involving learning disabled children. *International Journal of Social Research Methodology: Theory and Practice, 10, (1), 21-35.*

Kelly, B., Dowling, S. & Winter, K. (2013) *A Review of the Legislative and Policy Context in relation to Looked After Disabled Children and Young People in Northern Ireland.* Belfast: OFMDFM and Queen's University Belfast. Available at: http://www.ofmdfmni.gov.uk/index/equality-and-strategy/pfg-economics-statistics/equalityresearch.htm (accessed 09/04/14).

Kelly, B., Dowling, S. & Winter, K. (2015) *Profiling the population of disabled looked after children and young people in Northern Ireland.* Belfast: Queen's University Belfast and OFMDFM.

Kus Saillard, E. (2011) Systematic versus interpretive analysis with two CAQDAS packages: NVivo and MAXQDA, *Forum: Qualitative Social Research*, *12*(1), Art. 34

McNeilly, P., Macdonald, G. & Kelly, B. (2015): The Participation of Disabled Children and Young People: A Social Justice Perspective. *Child Care in Practice, 21,* (3), 266-286.

NISRA (2011) *Census 2011*. Data available at: http://www.ninis2.nisra.gov.uk/public/Theme.aspx?themeNumber=136&themeName=Census 2011. Accessed on 24/7/15.

Robson, C. (2011) *Real World research* (3rd edition). Wiley: West Sussex.

Appendix 1: Pen Pictures

Alicia, aged 16.

Alicia came into care following allegations of physical abuse. There had been a long history of police involvement with the family linked to domestic violence and aggressive behaviour in the home. This young person was placed in a mainstream children's residential home, which ended due to her threatening behaviour towards peers and staff. She returned home but her behaviour was considered to pose a risk to younger siblings and she moved on to two very short-term foster placements before going to another children's home, where she currently resides. Due to concerns about risk to her siblings, contact with her birth family is restricted to outside of the family home, although she remains voluntarily accommodated. Alicia was diagnosed with ASD when she was 16 years old. She is struggling to come to terms with this diagnosis and receives psychological support to help her understand how her impairment impacts on her sense of self and social relationships. Alicia feels that staff within the home where she lives have limited understanding of her impairment and measures that could be put in place to support her. Since coming into care, she has self-harmed and presented with suicidal ideation, which led to a short stay in a mental health assessment unit. She has also been arrested and prosecuted on several occasions, with convictions usually related to challenging situations within the home. More recently, she has stopped self-harming, in part, because she believes 'improved behaviour' may lead to a place in supported accommodation and possibly being permitted to spend more time with her family. Both she and her social worker feel that her currently placement is failing to meet her needs, risking further engagement in criminal behaviour. Her social worker has applied for placement in supported accommodation following the young person's preferred aftercare placement.

Joseph, aged 16.

Joseph has been living in an assessment and treatment centre for young people with learning disabilities and complex mental health needs for a couple of years, as a detained patient. He has been diagnosed with autism, severe learning disability, ADHD and epilepsy. He also presents with very challenging behaviours which can pose risks to himself or others. Prior to coming into care, he used short break services, however his family report that more support within the home and advice on behaviour management would have been advantageous. A shared care arrangement was introduced following an escalation in challenging behaviours. At this time the young person lived between his family home and a residential unit for young people with intellectual disabilities whilst continuing to use short breaks. Staff struggled to address his challenging behaviours, which led to a number of stays at the assessment and treatment unit where he eventually remained as a detained patient. He spends one night a week in his family home when his behaviour is settled and his family visit him almost every other day of the week. Joseph attends specialist

schooling in a therapeutic community where he has access to a classroom on his own, if needed. He is reported to require constant supervision and has two staff with him at all times who have received training on how best to manage his behaviour. His parents have not been able to avail of this training, although feel they would benefit from such training on how to manage behaviours during his overnight stays at home. Planning for transition to adult life is in the early stages for Joseph with adult disability services being informed about his needs and the therapeutic community beginning to consider the possibility of providing an adult residential placement.

Margaret, aged 14.

Margaret lives with her foster parents in a long-term placement which began as a short-term placement. She came into care following confirmed physical abuse and suspected sexual abuse. There is also a history of domestic violence within her birth family. She has been diagnosed as having a severe learning disability and attends the local special school. Margaret previously availed of regular short break care, however, these placements ended due to a change in circumstances for the carers and no alternatives being available. Her foster carer is finding it difficult to continue caring for her and urgently requested fortnightly short break support. Several risk related incidents within the foster family home have recently added to stress for her foster carer. As a result the current placement is unstable. The Trust are considering whether or not this current placement provides a long term care option for Margaret and are exploring alternative options. They have secured a placement in a residential short break unit, however, this provider requires a specialist risk assessment from an organisation who are refusing to complete the assessment as they do not feel it is in the child's best interests. The young person has monthly supervised contact with both birth parents, in addition to contact with her birth mother in the intervening two weeks.

Michael, aged 16.

This young person was relinquished into care when his mother left the country in his teenage years. Following a short stay with a short break carer, he moved to live with his current foster family. He has been diagnosed as having severe learning disability and autism. He has twice weekly contact with his father and spends a half day with his father one weekend per month. The whereabouts of his mother are currently unknown. He has two older siblings with whom he has occasional contact during visits to his father. Michael attends a special school and also accesses physiotherapy, occupational therapy and speech and language therapy at school. He also attends a youth group and a vocational training programme for disabled young people during the week. It is hoped that Michael will move into a training and employment placement there when he leaves school.

Gareth, aged 14.

Gareth moved to a short-term foster placement when he was admitted to care in his pre-school years. He was freed for adoption without parental consent, however continued efforts to identify an adoptive family were unsuccessful. He remained in a short-term foster placement for more than five years whilst waiting for adoption. His placement ended when his care plan from adoption to a long-term foster placement. Gareth then moved to a long-term foster care placement where he presents as very settled and happy. He refers to his current placement as his 'forever family'. Gareth has cerebral palsy, learning disability and ADHD. When he was younger, there were concerns about challenging behaviours, however, since moving to his current placement these have been addressed. Gareth has younger siblings who are all in care with a view to adoption. He has contact with his siblings quarterly and enjoys these contact visits. His birth parents are from the travelling community and the whereabouts of his parents are currently unknown. A short time ago, his parents applied to court to have contact with all of their children reinstated. At this time, he was highly anxious about being taken away from his foster family and expressed a wish to have no further contact with his parents. He agreed to send one card each year to his parents who have respected his decision. Gareth attends a special school where he enjoys meeting his friends, He also accesses physiotherapy, occupational therapy and speech and language therapy at school.

Shauna, aged 16.

Shauna lives in a kinship foster placement. She has been in care since birth as her parents' mental health conditions prevented them from being able to care for her. She spent most of her childhood living with grandparents, however, following a suicide attempt she revealed was very unhappy in her placement. Four moves followed between relative and non-relative foster placements, until she settled with her current kinship care placement. She has no contact with her birth mother and intermittent contact with her father. Shauna attends mainstream school and is ambitious for her academic future. She has been supported by fostering achievement throughout her school life, which she regards to have been a positive influence. She has experienced bullying at school and despite repeated interventions from social services, her carer does not feel this has been adequately dealt with by her school. Nevertheless, she has a strong friendship group and presents as resilient.

Connan, age 13.

Connan attends a special school where he is reported to be happy and thriving. He has a diagnosis of an intellectual disability and autism. He has returned home to the care of his birth parent following a period of time in foster care. His birth parent now had access to substantial short breaks to support the placement, including overnight

and day time activities. Previously, he had been relinquished into care by his mother who had not been able to cope with his care needs alongside that of his sister who had a severe mental health illness. She is a single parent with no informal family support. She believes that, if she had received enough support when she first asked for help, she would not have needed to place him in out-of-home care. Connan's sister now lives independently and, with access to short breaks, his mother is coping well. Although Connan would prefer not to avail of short breaks, his mother feels this support is essential to enable her to continue to care for him at home.

May, aged 9.

May was placed in care under a Care Order following safeguarding concerns related to substance misuse and the presence of inappropriate adults in her home. She was placed in a specialist out-of-area foster placement and was unable to continue to attend her special school where she had received a range of therapeutic supports. May has cerebral palsy and some additional health needs. She spent a short period in foster care before returning to live with her birth mother who worked closely with social services to have her child returned home. An application for the child to be discharged from care had been made and, given the progress her mother had made in dealing with addiction problems and taking control of her own life, this looked likely to be successful.

John, aged 15.

John has resided in a kinship foster placement with his grandmother since his early years. He was placed there under a Care Order following confirmed physical abuse. Initially, he had supervised contact with his mother but has not seen her for a couple of years despite social services attempts to re-establish contact as he worries about his mother's well being. The young person's father, who has a diagnosed mental health condition, also lives at the same address but has limited role in the young person's care. John attends a special unit in a mainstream school and is currently engaged in studying for GCSE's. He has plans to gain a qualification in a trade when he finishes school. He is currently waiting to meet his new social worker as he makes the transition to the 16+ team.

Ella, aged 4.

Ella lives in a long-term foster placement under a Care Order with one of her siblings where she is very settled. She was placed in care as a baby due to safeguarding concerns relating to neglect, emotional abuse and her parent not coping. She was born prematurely and has a number of residual health care needs. Although her development is delayed, she is progressing well at a special school, which she

enjoys. Ella has supervised contact with her birth mother (her father is deceased) and siblings, three of whom are also looked after, though the youngest sibling lives with her birth mother. Contact can be intermittent as her mother only has contact if all of her children are able to attend together. Her foster parent works hard to maintain the link with her birth family through looking at pictures together, but reports that the child never mentions her birth mother without prompting.

Codie, aged 5.

Codie was placed in care following the sudden death of his primary carer, his father. His mother's chronic illness made it difficult for her to provide him with care. Codie has been diagnosed as having a severe intellectual disability and complex health needs requiring 24 hour medical attention. He was voluntarily accommodated in a hospital setting and remained there as a social admission for almost one year. He then moved to a short-term foster placement but has remained there for over a year. A high level of support is in place to maintain the placement including regular support during the night. Codie's birth family have adapted their home to facilitate his return to their care. However, the possibility of a shared care arrangement with the birth family and foster family is being considered in terms of best meeting his needs. Throughout his time in foster care, Codie has had unsupervised contact with his mother and siblings twice a week, maintaining a strong connection with them whilst also being settled in his foster placement.

Adam, aged 14.

Adam has been in care for over four years and currently resides in an out-of-jurisdiction specialist therapeutic community. He has a diagnosis of autism. He was voluntarily accommodated due to his violent behaviour in the family home which posed risks to his younger siblings. His first year in care was fraught and he experienced repeated placement breakdowns in both foster and residential units, with ten placement moves. However, he is settled in his current placement. Adam has monthly contact with his birth mother and also regular contact with his siblings, apart from one sibling who is currently detained in care. Transition planning has commenced for Adam with placement and occupational options being investigated.

Aaron, aged 10.

Aaron resides in a long term foster placement where he has lived for the past five years. He has been diagnosed as having ASD. He has two sisters, one who is also looked after in another placement and one who lives with his birth mother. He is looked after on a Care Order and was taken into care due to neglect as well as suspected physical, emotional and sexual abuse. He has regular contact with his

birth mother and siblings but does not see his birth father. His care plan was changed from adoption to long term fostering as no adoptive parents had been identified and he was considered to be hard to place. Aaron attends a special school which he enjoys. He is settled in his foster setting and has a close relationship with his foster mother.

Darragh, aged 4.

Darragh is placed in a kinship foster setting with two birth siblings. He has global developmental delay and is undergoing assessment for ASD. Darragh was initially voluntarily accommodated but the Trust sought an interim and later full Care Order due to concerns about neglect and potential physical abuse. He remains on a Care Order. His mother has ceased contact, although this could change should she wish to re-establish contact. Darragh has weekly supervised contact with his father, which he enjoys. He attends a special school and is settling into the routine there. His carer reports that his behaviour can be challenging at home and she finds it difficult to set boundaries. His social worker has suggested parenting support classes to help her to manage his challenging behaviours.

Aoife, aged 7.

Aoife currently lives on a Care Order with her birth father and younger sibling. She was returned to her father's care after four years in kinship and non-relative foster placements, experiencing four moves during this time. She became looked after due to neglect, emotional abuse and substance abuse by both parents. Her father has worked closely with social services to deal with personal problems and adapt his parenting style in order to have both his children returned to his care. He is currently hoping that the case can return to court to discharge the Care Order. Aoife has regular contact with her grandparents and supervised contact with her mother. She has been diagnosed with an intellectual disability, foetal alcohol syndrome and global developmental delay. She currently attends a mainstream school where she accesses additional support and reported to be progressing very well.

Appendix 2: Protocol for Social Care Case File Reading

Pseudonym name of child:

Date of case file reading:

Name of Trust:

Name of child's field social worker:

Date of birth	Soscare number	Type(s) of impairment (if undiagnosed, reason for access to disability services/needs)	Age at diagnosis	Professional making diagnosis (if undiagnosed, professional assessing for access to disability services)	Family composition	Placement details of any LAC siblings	Parent's impairment

Demographic details of child and family

Family contact

Type of Contact	Frequency of Contact	Duration of contact	Location of contact	Identified contact issues
Contact with one or both parents				
Contact with siblings				
Contact with extended family				

LAC status and placement details

LAC Status (e.g. Care Order/Vol. Acc.)	Date became LAC	Recorded reason for becoming LAC	Placement type	Date LAC status ended (if applicable) and reason	Other details

Social work support/key contacts for (incl. staff changes/no. of social workers over time)

Field SW	Placement related SW (e.g. residential SW/ fostering SW)	Disability related SW	Other

Family support services

Name of Service	Details on type of service and need addressed	When service began	When service ended and reason (if applicable)

Critical incidents/issues leading to disabled becoming LAC

Critical incident/issue	Service response	Link with becoming LAC

Details of child protection issue	Procedures followed (incl. multi-disciplinary responses)	Link with becoming LAC	Child on 'register' (what register)	Reason why child on 'register'

Child protection procedures

LAC procedures

Frequency of LAC reviews	Participation of child (how, where recorded, outcome)	Participation of parent(s) (how, where recorded, outcome)	Key action points from reviews in care plan	Evidence of actions in care plan followed through/not

LAC Experience

Placement type	Duration of placement	Reason for placement change	Associated school change	Case planning re: permanence?
1				
2				
3				
4				

Other health and social care professionals involved in supporting disabled LAC

Professional / service	Nature and duration of contact	Key roles
Support worker (independent living/parenting)		
Community Nurse		
GP		
Psychologist		
Psychiatrist		
Domiciliary worker		
Speech Therapist		
Physiotherapist		
Occupational Therapist		
Hospital doctor		
Specialist		
Transition worker		
Therapeutic LAC SW		
Independent Visitor		
Independent Advocate		
Supported employment officer		
Other		

Additional information re: transition support

Transition planning	Involved professionals	Evidence of child's input	Evidence of parent's input

Educational experience

School type (mainstream, special unit/ school, at home, excluded)	Statement of SEN	Duration of school placement	Reasons for changes (if any)	Support for education development

Interventions with LAC

Type of intervention and purpose (e.g. referral / direct intervention)	Waiting time for service (if applicable)	Professional(s) involved	Links to assessment/ care plan	Next steps to follow on

Leaving care services (if applicable)

Extent of leaving care support	Support from 16+	Support from other professionals / services	Plans for post-care lives

Experience of criminal justice

Number of police cautions	Reason for cautions	Number of convictions	Reason for convictions	Action taken (e.g. community service)

Risk and management of risk

Risk taking behaviour	Intervention/support given/offered	Injury or harm consequent to risky behaviour

Short break usage amongst fully LAC

Placement type	Frequency and duration	Changes in placement type	Reason for change	Unmet need re: short breaks

Additional notes:

Appendix 3: Interview Topic Guides

Interview Topic Guide for Children and Young People

1. Establish Rapport, Communication Method & Assent

- Introductions and consent
- Establish an appropriate communication style - symbols, talking, personalised communication techniques, support required
- Explain research – number visits, what talk about/do during visits

2. Introduce 'All About Me' book & complete getting to know the child section:

- o Age
- o How I would describe myself...
    - Tell me about your likes/dislikes. What makes you happy / sad?
- o My day – use diary sheet to assist with this process

3. Exploration of Child Views & Experiences

- **Context of my life: experience of being in care**
    - o People in my life
        - Who do you see? How often? Is there someone that you would like to see more often that you do at the moment?
        - Who do you enjoy being with? Why? Is there anyone you don't like being with? Why?
        - Contact - What it is like to see my birth mum/dad, siblings or other members of birth family
    - o Where I live
        - What is it like to live where you do? Who else lives there?
        - What do you like about where you live and what do you not like? Are there things that you would want to change about where you live?
        - What's the best day of the week? Why?
    - o Changes in my life: school / placement changes / relationship changes

- Do you remember living somewhere else before you came to live here? Why did that change? Did someone explain to you what was happening? Did you understand?

- Any school changes? If you had to change schools, was it hard to make new friends? Did you settle in easily or was it difficult?

- My understanding and feelings about changes… e.g. why I do not live with my mum (and dad)**...** why you had to move?

- **Social work and other services**

    o Do you have a social worker (s)? What do you think of your social worker(s)? What sorts of things do they do for you?

    o Do you use any disability/mental health services? What do you think of them?

    o How could social workers do their job better? How could services be improved?

- **Taking part and being understood**

    o Having a say/being listened to
        - Do other people ask you what you think about things e.g. where you live, seeing your mum?
        - Do you think they listen to your opinion? Does what you say make a difference to what happens in your life?
        - Are there ways people could be better at listening to your views?
    o How others see me
        - Do you have any good friends? What would your friends say if they were describing you to someone else?
        - What would X (e.g. mum/carer/social worker) say about you?
    o How I see disability/mental health
    o What I like/would change about my life
        - Are there things you would like to be different? What things? Who/what could help to make things the way you want them to be?

- **My hopes and dreams for the future**

    o What are your dreams for the future?
    o Do you have big hopes for the future?
    o What would you like things to be like in 5 years from now?

Interview Topic Guide for Carers

Foster carers experience and perspectives

- How long you have been fostering (child)?
- What were the factors that led you to becoming their foster parent?
- Do you know the factors which led the child to becoming looked after?
- What do you think is the child's understanding of the factors which led them to become looked after?

Placements and placement changes

- If applicable, what factors led to the child leaving the previous placement(s)?
- What was the child's response to placement changes?
- Does the child have contact with previous carers?

Contact

- Does the child have contact with her/his birth family? If yes, with whom? How often do they see the relative? Is this supervised? What role does foster parent/carer have in contact arrangements?
- What is the child's response to contact? Are the particular things you do to prepare them for contact / support them before or afterwards?

Child's Needs

- Can you tell me what you consider the key needs of the child to be?
- How do you go about trying to meet these needs?
- How does their disability / mental health impact on how you care for them?
- Do you access support services / short breaks?
- What are the personal impacts of your caring role on you and your family?

Interface with professional services

- What is your experience of LAC procedures?
- Are you satisfied with the support you have received in caring for the child?
- How would you describe your relationship with professionals in the child's life?
- Do you have any examples of good practice or positive support to report?
- What do you think could be improved in relation to policy and practice?

Child's involvement in decision making
- How is the child involved in making decisions about things which affect their lives (e.g. participation in reviews/ decisions)?
- Do you think their opinion is heard and valued?
- Do you think more could be done to ensure that the child has their voice heard about matters which affect them?

Interview Topic Guide for Birth Parents

Family circumstances

- Family composition (e.g. marital status, siblings)
- Who lives in the home?
- Employment and income

Factors leading to their child becoming looked after

- From your perspective what led to your child going into care?
- What support services were offered to you to try to keep your child at home?
- What disability, mental health or child welfare services involved?

Disability

- Parental experience of child's disability/mental health related needs: do they have a diagnosis? What is the nature of their disability/MH need?
- What is the impact of disability/MH needs on their lives now?
- What impact did it have on the decision for them to go into care?

Parents' own needs / disability

- Would you consider yourself to be in good health?
- Have you ever experienced mental ill health or disability?

Satisfaction with placement, family support and services for their child

- What you think of their current placement? Does it meet her needs? Does it take into account her disability?
- Is there anything you would like to change about their placement?
- Tell us about their other placements and how well they meet their needs

School:

- Are they engaged in school?
- If so, do they enjoy school? Have they experiences school changes? How has that impacted on their education?
- If not, when did they leave and what are their plans for training or employment opportunities?

Contact arrangements

- How often do you have contact? Where? Is it supported/supervised

- What are your feelings about the contact that you have?

- Did you contact always remain the same or were there changes in frequency?

- Do other family members have contact?

Participation in decisions affecting their child's life

- Do you feel that your views are taken into account when decisions are made?

- Are you consulted? In person/by phone/in writing?

Experience of LAC procedures

- Tell me about your experience of the LAC process? Are you involved in care planning and reviews?

- Are there any parts of the process that you would change if you could?

Professional relationships

- How would you describe your relationship with social workers involved with your child? Is there anything you would you change about them?

- What key messages would you give to social workers and other professionals about supporting families with disabled children?

- Do you have any examples of when you had good support from professionals? What made this a more positive experience for you?

Transition:

- What do you see as their key needs as they leave care?

- Is there a pathway plan /l transition plan? What are the main issues/actions?

- Are they taking part in decisions about their post-care lives?

- Are you participating in these decisions / pathway planning? How well did you feel involved/listened to?

The future:

- What are your hopes and concerns for them now?

- Where would you like things to be 5 years from now?

Interview Topic Guide for Social Workers

Organisational and Trust policy issues

- What are the key policies guiding practice with DLAC? Any specific to DLAC?

- How are services organised for disabled LAC?

    o Who leads on these services? (CWD / LAC teams)?

    o If co-working is involved, how well does it work? Issues/challenges?

    o Are there any differences in services for LAC with ASD?

    o And those with borderline disability / not reaching threshold for CWD services - are there any differences in services for those LAC? What is the threshold for access to CWD services?

    o Co-existing disability & mental health - who leads on those cases?

    o Do DLAC with MH needs access CAMHS? LAC Sp.ist Therapeutic services? If not, why not? If yes, what are the issues/challenges?

    o How well do various teams/services work together?

    o Do you have any concerns about unmet need?

Multi-disciplinary working across service areas

- How well are services configured to facilitate multi-disciplinary working across services to meet the needs of DLAC?

- Are there established links with education, health, youth services, disability services, children's services? What are the pathways to multi-disciplinary working?

- Are there challenges relating to who takes lead responsibility?

Training

- And what LAC training is provided for social workers in your CWD team?

- What disability-related training is provided for LAC social workers?

- Are there gaps in training for staff in your team re. working with disabled LAC?

Disabled children becoming looked after

- What efforts are made to support families to continue to care for DCYP?

- What would escalate the situation to meet the threshold for risk of significant harm and admission to care for a disabled child?

- What are the characteristics of disabled LAC on the edge of care? What prevents their admission to care?

Disabled children coming into care

- What are the issues for practitioners when disabled children come into care? (e.g. placement options/links with family/permanency)

- What impact does impairment have on placements for DLAC?

- What are the main reasons for DCYP to become looked after?

Disabled children looked after due to short breaks

- What are your thoughts on children who are LAC due to short break usage?

- Would you have any concerns if policy changed so they are no longer categorised as looked after?

- What would you recommend to replace the current arrangement?

Experiences of working with disabled LAC

- What do you consider to be the key needs of disabled looked after children?

- Are there particular support needs for their parents? And carers?

- In your opinion, how well does the public care system meet the needs of DLAC with various impairment types?

- What is the impact of impairment on experiences of DLAC, incl. placement?

- Are there particular issues re. the LAC processes/procedures for DCYP?

- What are the issues relating to family contact after DCYP have become LAC?

- In your experience, is there the same emphasis on permanency planning for DLAC as there is for non-disabled LAC? What are the challenges to seeking permanency for DLAC?

- What are the issues and challenges relating to the placement of DLAC in: out of area placement in NI? Out of jurisdiction in GB?

- What are the challenges for practitioners working with disabled LAC?

Participation

- In your experience, how well do DLAC participate in decisions?

- What is the extent of their involvement in LAC reviews and care planning? How is this facilitated and put into action?

Good practice

- Do you have any examples of good practice re. meeting the needs of DLAC? What makes these good practice examples?

- Are there any other issues re. disabled LAC you would like this research to highlight?

Interview Topic Guide for Senior Managers

Organisational and Policy Issues

- What are the policies and procedures primarily guiding social work with disabled looked after children?   Prompt: regional and specific Trust policy?
- What aspects of policy, procedures and practice work well in meeting the needs of disabled LAC? And what needs improvement?
- How are services organised for disabled LAC?
    - o Who leads on these services? (CWD or LAC teams)?
    - o If co-working is involved, how well does it work? Issues/challenges?
    - o Are there any differences in services for LAC with ASD?
    - o For those with borderline disability/not reaching thresholds for CWD?
    - o And for those with co-existing disability and mental health needs? Who leads on those cases? Do disabled LAC with mental health needs have access to CAMHS? What are the issues/challenges?
- What disability-related training is provided for LAC social workers? And what LAC training is provided for social workers in CWD teams?
- Are there gaps in training for staff working with DLAC across teams?

Multi-disciplinary working across service areas

- How well are teams and services configured to facilitate multi-disciplinary working in terms of meeting disabled LAC's changing needs and care planning? Are there challenges relating to who takes lead responsibility?
- Are there established links with cross-sector services (e.g. education)? What are the pathways to multi-disciplinary working? How well do various teams/services work together?

Disabled children becoming looked after

- What are the issues at play when making efforts to support families to continue to care for their disabled children? What are the common characteristics of these types of cases?

    What would escalate the situation to meet the threshold for risk of significant harm and admission to care? What prevents their admission to care?

Disabled children coming into care

- What are the issues for practitioners when disabled children come into care? (e.g. placement options/links with family/permanency)
- What impact does impairment have on the placement of disabled LAC?

Disabled children looked after due to short breaks

- What are your views on children being LAC due to short break usage?

- Would you have any concerns if the policy changed so they are no longer categorised as looked after?

- If you think an alternative would be appropriate, what would you recommend to replace this current arrangement?

- What are the issues at play for disabled children making extensive use of short breaks (65+ days) in your Trust area? Why are they availing of intensive support? Is there a link to concerns about parental capacity for some cases? Would you say these children are on the edge of care?

Experiences of working with disabled LAC

- How well does the public care system meet the needs of disabled LAC?

- Is there the same emphasis on permanency planning for DLAC as there is for non-disabled LAC? What are the challenges to seeking permanency for DLAC?

- What are the issues and challenges relating to the placement of disabled LAC in out of area placement in NI or out of jurisdiction in GB?

Disabled LAC access to services

- How much access do disabled LAC have to disability services?

- What level of access do disabled LAC have to CAMHS/LAC Specialist Therapeutic services? Do you have any concerns about unmet need?

Participation

- How well do disabled LAC participate in decisions affecting their lives? LAC reviews and care planning? How is this facilitated and put into action?

Disabled LAC Leaving Care

- What are the organisational arrangements for disabled LAC leaving care? Who holds responsibility? When are cases transferred to 16+ teams?

Good practice

- Can you identify examples of good practice in relation to disabled LAC?

- Are there any other issues re. disabled LAC you would like this research to highlight?