



# **Disabled Children and Young People in Out-of-Home Care**

## **Summary Report**

**Berni Kelly, Sandra Dowling and Karen Winter**

**This report can be cited as:** Kelly, B., Dowling, S. & Winter, K. (2016) *Disabled children and young people in out-of-home care: summary report*. Belfast: QUB & OFMDFM.

## **Acknowledgements**

We would like to thank the OFMDFM for funding our three year study on the over-representation of disabled children and young people in public care in NI, with special thanks to Adele McCauley and Pauline Donnan for their support and feedback throughout the study.

We also extend our sincere thanks to the following members of the professional advisory group who provided much guidance and support for the study: Kieran McShane, Patricia Nicholl, Professor Roy McConkey, Rosemary Murray, Dr Dominic McSherry, Janet Allen, Paschal McKeown and Eilis McDaniel. We are also very grateful to the disabled children and young people from the Barnardo's Sixth Sense group who formed the children's advisory group and collaborated with the researcher to develop recruitment materials, including the production of an accessible DVD.

Of course, this report would not have been possible without the involvement of the disabled children, birth parents, carers and social workers who agreed to take part. We greatly appreciate their willingness to permit access to their case files and to participate in interviews which have provided rich data on the needs and experiences of disabled children and young people in our care system. Interviews often involved revisiting past experiences, current challenging situations and emotional reflections on children's pathways through care. In this context, we would like to give our sincere thanks to the disabled children and young people, parents and carers who welcomed the researcher into their homes and shared their unique personal experiences.

Finally, this study benefitted much from the support and effort of social work teams and senior management in each of the five Health and Social Care Trusts who facilitated survey data collection. We would like to thank the five senior managers who guided the process of data collection in each of their Trusts and contributed their expert advice at our advisory group meetings: Kate Kelly, Kate Courtenay, Pauline McDonald, Jacqui McGarvey and Nuala Mangan. We would also like to extend our gratitude to the team leaders and social workers across NI who gave up their time to complete profiling surveys, participate in interviews and facilitate access to disabled children and their case files. Despite very busy caseloads and challenging casework, these social workers took time to share their professional perspectives and contribute to the research agenda for looked after disabled children and young people.

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## **1.0 INTRODUCTION**

In the UK, the traditional practice of routinely placing disabled children in institutional care, segregated from community life, and separated from family life, has ended. The majority of disabled children and young people now live with their birth families, many of who draw on the support of health and social services when required. However, it is still the case that the numbers of disabled children who are looked after away from home for some or all of the time exceeds that of their non-disabled peers (DHSSPSNI, 2015; Stalker & McArthur, 2010). Furthermore, disabled children who successfully achieve permanence in substitute families falls short of the rates recorded for non-disabled children (Baker, 2007). This is despite major change in research and social policy agendas which promote the equal rights of disabled children to high standards of out-of-home care and routes to permanency.

Despite these concerns, and with the exception of a few important local studies, there remains a noticeable lack of research regarding the numbers, characteristics and experiences of this vulnerable group of children looked after by social services. It is within this context that the OFMDFM funded the current study to examine the over-representation of disabled children and young people in out-of-home care in Northern Ireland (NI).

### ***Structure of report***

This report presents a summary of the key findings of each stage of the study. We encourage readers to consult the full reports on each stage of the study for further details (Dowling et al., 2013; Kelly et al., 2013; Kelly et al., 2015; Kelly et al., 2016). Each report is available on the following OFMDFM web link: <http://www.ofmdfmi.gov.uk/index/equality-and-strategy/pfg-economics-statistics/equalityresearch.htm>.

The summary begins with an overview of the service context for the study and the statutory data return on the general population of children and young people in care at the time of the study (HSBC, 2013). A summary of key policies and the findings of the literature review are then presented. This is followed by an outline of the methodological approach, including definitions of disability and children in out-of-home care as operationalised in this research study.

An overview of the profile of disabled children and young people in out-of-home care in NI is then presented, divided into two distinct groups within this population: those who are fully looked after (in full-time care of the state) and those who are looked after due to short break usage. For both groups, profile information is provided on: reasons for care entry; prevalence of types of disability; family background; legal status; placement type and change; contact with family; use of short breaks; education; safeguarding and risk; additional needs; and access to support services.

Following the profile overview, the report provides a summary of the findings of the case study stage of the study which highlights the views and perspectives of disabled children and young people in out-of-home care and the perspectives of their birth parents, carers and social workers. The report then concludes with recommendations for future research, policy and practice.

## **2.0 BACKGROUND TO THE STUDY**

In the planning and conduct of the study, it was important to note the service context for disabled looked after children in NI

### ***The service context for looked after disabled children in NI***

Health and social care services in NI are delivered through an integrated service model with a commissioning Health and Social Care Board (HSCB) and five Health and Social Care Trusts (HSCTs). The HSCB bears the responsibility for commissioning services, managing resources as well as performance management and service improvement. The following five HSCTs have the main responsibility for the delivery of statutory health and social care services in their region: Western (WHSCT), Northern (NHSCT), Southern (SHSCT), South- Eastern (SEHSCT) and Belfast (BHSCT). The geographical spread differs considerably across Trusts, with the NHSCT and WHSCT covering the largest geographical areas. The BHSCT provides for a densely populated urban area, whilst the remaining HSCTs cover the needs of a mixed population, some in urban zones, others in remote rural locations. The WHSCT has a dual challenge of service provision for a widely spread rural population whilst at the same time serving the needs of the province's second largest city.

Social service support for disabled children in out-of-home care<sup>1</sup> is provided across a range of social work teams in each HSCT including: Children with Disability (CWD) Teams, Looked After Children (LAC) Teams, 16+ Teams and Family Intervention/Family Support Teams (FIT or FIS). LAC Teams have the main responsibility for all children in care in NI, including disabled children, in all but one Trust in NI (where CWD maintain responsibility). CWD teams may co-work on cases of disabled children held by LAC teams (fully looked after) but they also have the main responsibility for disabled children looked after due to short break usage.

Under the Children (NI) Order 1995 children in NI who use short breaks for more than 24 hours continuously are also defined as looked after children. CWD usually

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<sup>1</sup> 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.

hold responsibility for these cases, including the implementation of all LAC procedures for these children. Disabled children in out-of-home care case worked by CWD teams are likely to have an intellectual, physical or sensory impairment. Whilst some of these children may also have recognised mental health needs, they will not be case worked within CWD on the basis of mental health need alone. The latter group would be referred to CAMHS or LAC Specialist Therapeutic services. Family Intervention Teams (FIT/FIS) have a remit of supporting children and families and preventing admission to care, if possible. However, in some Trusts they may have a small number of disabled children on their caseloads if they do not meet the threshold for CWD support, often those not yet diagnosed or with borderline to mild levels of impairment.

In relation to the service context for disabled children in out-of-home care within each of the five HSCTs, a number of issues are worth highlighting to provide a context for the findings in relation to the profile of this population.

1. Regional services, such as the Iveagh and Beechcroft in-patient assessment and treatment facilities, have a higher level of usage amongst some Trusts compared with others. This may be because similar services exist within the Trust area or it may be due to the geographical distance and the challenges for young people and their families of out of area placements, heightened at times of particular vulnerability for young people. Residential placements are also available in the Camphill Community which is a regional service located within the South Eastern Trust.
2. There appears to be variation between Trusts in terms of access to CAMHS for children and young people with intellectual disabilities. Some Trusts rely on psychiatric learning disability services, often accessed through adult services. For others, CAMHS is open or partially open to those with an intellectual disability, depending on the severity of the impairment.
3. Greater usage of services in some areas may reflect increased availability of particular services in that locality rather than increased need. For example, more children in the WHSCT have access to residential short breaks due to the launch of a new residential unit. However, this may alter as the service is extended to include more children and young people with physical disabilities and ASD.
4. A limited number of out-of-area placements in England or Scotland are made across the HSCTs, usually for children and young people with severe levels of impairment, complex health needs and/or challenging behaviours. This is due to the reported lack of suitable residential placement for these children within NI.
5. Within Trusts the availability of some services is variable. For example, a particular service may be available in one part of the Trust, but because of

distance, travel logistics and costs is not available or accessible to those residing at a distance from the service. This is particularly relevant to HSCTs with a wider geographical spread with greater availability of services in urban areas.

Statistics on the LAC population in NI during the time period of the study are available from the HSCB's Delegated Statutory Function (DSF) data which is collected bi-annually (HSCB, 2013) and the Departmental statistical bulletin on children in care in NI 2013-14 (DHSSPS, 2015), although comparisons across datasets are limited by the different time frames for data collection and variances in definitions of disability. The other source of data relevant to this report is the 2011 census information on the wider population of children and young people in NI. According to this most recent census data, there are 456,059 children and young people (0-18 years) in NI and 7% of these are disabled (NISRA, 2011).

In relation to the LAC population at the time of the study, the DSF report on children in care at 30 September 2013 (the end of the data collection period for the current study) identified 2,892 LAC in NI, the highest number recorded in twelve years. In relation to spread across HSCTs, the largest number were recorded in the BHSCT (25%) and the smallest number were in the WHSCT (17%), to some extent reflecting trends in geographies and childhood populations in each Trust area. There were almost equal proportions of females (48%) and males (52%) in the LAC population, with most in the 5-11 year age range (33%) and lowest numbers in the 16+ category (18%).

Within the general LAC population, 54% were placed under a Care Order; with over a quarter (28%) being voluntarily accommodated and 16% subject to an Interim Care Order. The length of time in care peaked at 1-3 years (31%), with 27% had been looked after for less than one year (16% for 3-5 years, 17% for 5-10 years and <10% for over 10 years). The majority resided in foster placements (39% non-relative and 32% kinship settings). Other placement types included being placed at home (11%) or in residential care (7%). Most LAC (76%) had not experienced a placement move; 8% had moved once, 4% had experienced two placement changes, and 12% had moved on more than three occasions. Overall, 8% of LAC were on the child protection register, mostly those in the youngest 0-4 age group (46%).

The DSF report identified a total of 333 fully looked after disabled children, representing 11.5% of the general LAC population and indicating that disabled children are over-represented in the general LAC population in NI (HSCB, 2013). The highest percentages of these were in the BHSCT (42%) and NHSCT (35%) with very small numbers reported in the other three Trusts. The majority of fully looked after disabled children (63%) were reported to have an intellectual disability; followed

by those assessed as being on the autistic spectrum or having ADHD (19%); physical/sensory impairment (11%) ; and 7% were in the 'other' category. In addition to data on the number of fully looked after disabled children, the DSF report also identified a total of 348 LAC who had a Statement of Special Educational Needs (SEN). There are no further disaggregated figures for fully looked after disabled children as available reports focus on the LAC population as a whole (disabled and non-disabled children together).

In relation to the mental health needs of the LAC population, the only figure available in the DSF Report (2013) is that 1.1% (n=32) LAC were awaiting assessment or treatment with Child and Adolescent Mental Health Services (CAMHS). Further information is provided in the DSF report on the mental health needs of the leaving care population with 16.8% of care leavers reported to be receiving treatment for mental health concerns and 9.1% receiving treatment for self-harming behaviours.

### **3.0 POLICY CONTEXT**

As there is no overarching piece of law or policy specifically for disabled children and/or disabled children in care, the policy context for the study draws on a policy focused on disability or children generally, within the context of wider rights based law and policy.

#### **3.1 Rights-based policy**

In an international rights context, there are three key policies of relevance: the *European Convention on Human Rights (ECHR) (1953)*; the *United Nations Convention on the Rights of the Child (UNCRC) (1989)*; and the *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006)*. The first of these, the *ECHR (1953)*, establishes fundamental human rights principles, which are applicable to both adults and children whilst the United Nations Conventions focus on two groups who are particularly vulnerable to discrimination.

The *UN Convention on the Rights of the Child (1989)* details human rights and protections with specific reference to children who are deemed vulnerable given their age and care and protection needs. The rights of disabled children are also addressed in the *UN Convention on the Rights of Persons with Disabilities (2006)* which is applicable to both adults and children and aims to address the rights of disabled people who are vulnerable to unequal treatment or discrimination on the grounds of disability.

Aligned to these international conventions, important rights-based law has also been introduced in NI. The *Human Rights Act (1998)* enables individuals to have greater access to challenge rights violations outlined in the ECHR by enabling cases to be

heard in UK courts. The *Northern Ireland Act (1998)* established the Equality Commission NI whose role is to oversee discrimination and equality law. Central to protections for disabled people is Section 75 of the *Northern Ireland Act (1998)* which imposes statutory obligations on public bodies to promote equality of opportunity between disabled and non-disabled people.

The *Disability Discrimination Act (DDA) (1996)* aims to eliminate discrimination on the basis of disability and promote equality of opportunity. The amendments to the DDA (1996) introduced by the *Disability Discrimination Order (NI) (DDO) (2006)* broaden the definition of disability and require public bodies to promote positive attitudes towards disabled people and develop strategies to broaden their participation in public life. This legislation provides overarching mechanisms through which equal access to rights by all people are enabled and supported.

However, despite these international and local rights-based policies, research confirms some of the ongoing challenges that exist in relation to the actualisation of disabled children's rights (Harper *et al.*, 2012). The prevailing social and environmental climate creates a significant barrier with the high prevalence of childhood poverty and social isolation experienced by disabled children and their families (Dowling *et al.*, 2012; Haydon, 2007; Monteith *et al.*, 2009; Emerson *et al.*, 2010). There are also concerns regarding availability of short break services, access to assessments of need and educational supports, and bullying of disabled children (Mencap, 2007; Monteith *et al.*, 2009).

### **3.2 Child care policy**

There are four overarching policy documents which provide strategic direction to contemporary health and social care policy in NI: *Our Children, Our Young People, Our Pledge (2006)* 10-year children's strategy aimed at improving outcomes for children and young people; *Transforming Your Care (2011)* review of health and social care in NI; the *Child Poverty Strategy (2011)* which presents a strategic framework for eradicating child poverty in NI by 2020; and the *Strategy to Improve the Lives of Disabled People (2012)*. These documents emphasise family support and quality universal services alongside targeted interventions for those in particular need or most at risk of disadvantage and marginalisation, including looked after children and disabled children.

In addition to these wider strategic policy documents, child care practice in NI is guided by children's legislation. The *Children (NI) Order (1995)* is the primary statute regulating the care and protection of children. It endorses the view that children are best cared for by their families however, provides guidelines and regulation for state intervention in the care of children where they are at risk of harm. A central principle of the *Children Order* is the concept of 'best interest' where the welfare of the child is

central to decision making. The associated Guidance and Regulations and subsequent *Children (1995 Order) (Amendment) (Children's Services Planning) Order (NI) 1998* address statutory planning processes and requirements in relation to, looked after children and disabled children. The *Children's Homes Regulations NI (2005)* guide process and practice in relation to the welfare of children and the management of children's homes.

The *Children (Leaving Care) Act (NI) (2002)*, *Children (Leaving Care) Regulations (NI) (2005)* and *Leaving and Aftercare: Volume Eight Guidance and Regulations* (DHSSPSNI, 2005) provide detailed guidelines and regulation in relation to young people who are leaving care. Finally, the Standards for Leaving Care Services in NI (DHSSPSNI, 2012d) draw on the outcome statements from the 10-year children's strategy to establish core standards for services aimed at supporting young people leaving care.

There are also core strategic policy documents guiding child care policy and practice. *Care Matters* (DHSSPSNI, 2007) is a strategic document setting out a framework for the delivery and development of child and family services. The following year *Understanding the Needs of Children in Northern Ireland (UNOCINI) (2008)* was introduced to ensure a single assessment framework for identifying children's needs. It is underpinned by a whole child approach and includes specific guidance in relation to assessing need across a range of pathways.

*Families Matter* (DHSSPSNI, 2009) focuses on the child within the context of the whole family and is attentive to the prevention of family breakdown and a whole child, family-centred approach, identifying the family as the best environment in which to raise children, if it is in their best interests. Poorer health outcomes for looked after children are specified in this strategy and reference to disabled children highlights the benefits of early diagnosis, social inclusion and choice for disabled children and their families.

The *Healthy Child, Healthy Future* (DHSSPSNI, 2010a) strategy outlines a health promotion programme targeted at all children in NI including looked after and disabled children. It places considerable emphasis on the role of parents and families in the promotion of good health and the prevention of illness.

The *Children and Young People's Strategic Partnership* (CYPSP) was formally established in early 2011 to facilitate an integrated, cross-sectoral approach to children's services planning with a focus on the outcomes identified in the 10-year strategy. The CYPSP adopts a rights framework and strongly advocates for the views of children and young people are included in planning and decision-making

processes. Related planning documents emphasise early intervention, prevention and joined up services.

Finally, the RQIA (2013) reports on *Community Services for Children with a Disability and Safeguarding Children and Vulnerable Adults in Hospitals* outline the findings of a review of community services and an inspection of safeguarding practice for those residing in mental health and learning disability hospitals. These reports highlight good practice and areas where improvements are required, including issues relating to the duration and review of children's placements in such hospital settings and shortfalls in short break provision.

### **3.3 Disability and mental health policy**

In addition to this broader policy context, there is specific legislation relating to disabled people. Although dating back several decades, the *Chronically Sick and Disabled Persons (NI) Act (1978)*, the *Disabled Persons (NI) Act (1989)* and the *Mental Health (NI) Order (1986)* have continued salience as they make provision for assessment of need and provision of treatment and services to meet identified needs rather than a one size fits all model of service provision. The NI Executive are currently introducing new mental capacity legislation which will combine capacity and mental health law into a single legal framework which will apply to people aged 16 and over.

The *Carers and Direct Payments Act (2002)* further extends a needs based approach with the introduction of direct payments and carers' assessments. Although proposed changes to welfare benefits brought forward in the *Welfare Reform Bill* are likely to impact on the financial situation of disabled young people as well as parents of disabled children. The *Autism Act (2011)* broadens the definition of disability outlined in the *Disability Discrimination Act (1996)* enabling people with autism to have greater access to services and benefits, as well as instructing government departments to develop a strategy and service plan for people with autism.

Over the last decade, a key driver of learning disability and mental health policy has been '*The Bamford Review*' which produced a range of policy documents including the *Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland (2005)* and *A Vision of a Comprehensive Child and Adolescent Mental Health Service (2006)*. Foundational principles of these documents include the promotion of social inclusion and empowerment, collaborative working and personalised support to individuals. In addition, the vision for CAMHS emphasises the promotion of mental health, strategies to prevent the development of mental ill health and accessible and effective treatment of those with mental health needs.

In response to the strategic vision laid out in the Bamford reports the DHSSPSNI developed an *Action Plan for Delivering the Bamford Vision 2009-2011*. The evaluation of this action plan in 2012 noted progress in relation to the development of an early years strategy and family support pathways, an increase in residential short break provision and the implementation of the ASD action plan (DHSSPSNI, 2012a). The revised action plan for the period 2012-2015 (DHSSPSNI, 2012b), however, identified 76 actions for improvement including: early intervention; supporting carers and families; tailoring services to individual needs using a stepped care approach; and working collaboratively to address barriers to social inclusion and participation.

Similarly, the *Child and Adolescent Mental Health Services (CAMHS) Service Model (DHSSPS 2012c)* emphasises prevention, early intervention, recovery and a stepped care model to ensure services are matched to service user need. In addition, a whole systems collaborative approach is advocated to effectively link primary care, child health, social care services and specialist CAMHS. Amongst those identified in this document as being more vulnerable are looked after children and those with a learning disability.

Further relevant policy documents include the *Learning Disability Service Framework* (DHSSPSNI, 2012e, updated in 2015) and the *Physical and Sensory Disability Strategy 2011-2015* (DHSSPSNI, 2012f) which set out standards for the planning and provision of health and social care services to children and adults with various impairments and places an emphasis on taking service users' views into account in developing and monitoring standards. Finally, the *Autism Strategy (2013)*, developed in response to the requirements of the *Autism Act (2011)*, addresses definitions and prevalence and proposes a vision of inclusion for people with autism in cultural, social, political and economic life.

### **3.4 Education policy**

The Department of Education NI (DENI) aims to ensure that the conditions for each child to fulfil their educational potential are available. Some children need additional support and amongst these looked after children are identified as at particular risk of not meeting their educational potential. The *Education (Northern Ireland) Order 1996* as amended by the *Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO)* is the main legislation on special education in NI. In 2012, DENI launched a consultation focused on reviewing Special Educational Needs (SEN) and inclusion. Following this consultation, at the time of the commencement of the study, plans were underway to introduce the concept of Additional Educational Needs (AEN), the establishment of a Personal Learning Plan (PLP) for students with SEN or AEN to replace Individualised Education Plans, new rights of appeal for parents and annual plans for SEN supports and services available to schools and

SEN pupils. The Department indicated that new SEN and inclusion policy should provide better guidance and support for schools on how to deliver effective teaching and learning to children facing barriers to learning.

The strategic policy document *Every School a Good School (DENI, 2009)* endorses an inclusive and child-centred approach in education, whilst also recognising the impact of a child's wider experiences in their familial and social environments on their engagement with and experience of education. The *Early Years Strategy (DENI, 2010)* highlights the importance of the early years as a foundational time for children when educational interventions can reduce the later impact of social or material disadvantage.

### **3.5 Summary**

This review of policy conducted in 2012 provided the context for the design of the study. Since that time there have been further policy developments. For example, the introduction of the Children's Services Co-operation Bill and the publication of the Donaldson Report on improving health and social care governance arrangements in 2014; and the introduction of the SEN and Disability Bill in 2015. These policy developments continue to reflect many of the same themes emerging from this policy review, in particular, the importance of working together to improve outcomes for children and young people, promoting self-management and recovery, improving health and social care systems and promoting service user involvement.

The following five overarching themes are consistently evident throughout the range of policy documents available, from international human rights instruments to domestic legislation and policy.

- A central underpinning principle which directly impacts on disabled children and young people is that of equality, alongside a focus on social inclusion and anti-discrimination. This is evident both in the spirit of documents as well as in practice guidance and policy recommendations.
- The 'whole child' model is a key tenet of child and family policy, underlining the interactive and diverse factors that impact on disabled children's lives which exert a combined but varied influence on child development, wellbeing and upbringing.
- The family is emphasised as having a central role in children's lives and documents highlight the foundational impact of family circumstances and wellbeing on children's upbringing. Whilst the family is recognised to be of central importance, the best interests of the child are also emphasised, and it is noted that the family may not always be the most beneficial environment for all children.

- The importance of seeking the views of children, young people and their families is enshrined in human rights instruments and is a central feature of legislation and policy documents. It is a requirement for service providers to consult with children and young people, and to make suitable adjustments to enable the participation of those who do not use speech to communicate.
- In terms of service style, common themes within the legislation and policy documents include early identification of need and timely intervention, multi-agency working and person-centred service provision. These approaches to service delivery are identified as increasing the potential to produce improved outcomes for children and young people.

Disabled children in out-of-home care are subsumed within the policy documents relating to both disabled people and children. However, they do not feature strongly in the spectrum of policy and legislation reviewed as a distinct group requiring targeted attention. Consideration of law and policy relating to disabled looked after children requires a read across a range of documents and policy areas. Given the danger, therefore, that their particular needs and experiences may be ignored, more focused and holistic consideration of this particular group is required in future policy initiatives.

### ***Key Messages***

There is a high degree of consistency in themes across the range of disability, mental health and children's policy. A whole child, rights-based approach is evident, alongside an emphasis on inter-agency collaboration, person-centredness and timely, community-based care and targeted interventions. However, the invisibility of disabled looked after children in policy and strategy documents is notable. Children's policy often pays only brief attention to the particular needs and circumstances of disabled children, whilst children are often a subsidiary concern of disability policy. The particular needs of disabled looked after children are rarely mentioned within policy documents. Given the multiplicity and complexity of challenges facing disabled looked after children, and the poorer outcomes reported for this group of children, greater attention should be paid to their specific and diverse needs in policy documents. Such policy direction should take account of these children's experiences of the child care system and disabling social barriers impacting on their lives. Increased reference to disabled looked after children in policy documents should help to raise awareness of their particular needs and to firmly embed disabled looked after children within the broader children's social care agenda for action and change.

## **4.0 LITERATURE REVIEW**

In the first year of the study, the research team undertook a review of literature on out-of-home care for disabled children and young people to identify key findings from previous research and to inform the design of the research instruments (Dowling et al., 2013). The literature search identified 28 publications based on empirical studies and 30 relevant theoretical or commentary publications. Most publications were from the UK, USA or Canada, with a smaller body of work from Australia and New Zealand.

### **4.1 Prevalence of disability**

Various definitions of disability and care experience are used across jurisdictions and service contexts. For example, some studies include children solely with emotional and behaviour challenges under the heading of disability or mental health. Despite these definitional challenges, it is apparent that disabled children form a significant portion of the looked after child population across the UK and in other countries (Braddock et al., 2001; Gordon et al., 2000; Read & Harrison, 2002; Schofield et al., 2007; Sullivan & Knutson, 2000; Trout et al., 2009; Lightfoot et al., 2011). For example, in a UK study by Schofield et al. (2007) it was found that of children who had been looked after for 4 years or more, 34% of the sample were disabled or had an on-going health condition.

Although there is a lack of research knowledge that is disability type specific in its focus, that which does exist indicates that there is a higher prevalence of males compared to females and that in terms of impairment type, intellectual disabilities are more commonly represented (Laan et al., 2001; McConkey et al., 2004a; Rosenberg & Robinson, 2004; Taggart et al., 2007; Trout et al., 2009). Furthermore, the numbers of children with ongoing mental health difficulties are consistently reported as extremely high in the looked after child population in the UK (Cousins et al., 2010; Meltzer et al., 2003; Taggart et al., 2007; Teggart & Menary, 2005) and internationally (Golding, 2012; Milburn et al., 2008; Pecora et al., 2009; Tarren-Sweeney, 2008). For example, in Denmark, 20% of looked after children are reported to have a psychiatric diagnosis and up to 48% rate as 'abnormal' on the Strengths and Difficulties Questionnaire (SDQ) (Egelund & Lausten, 2009).

Trajectories of causality are unknown, therefore, it is unclear whether vulnerability to mental health difficulties is precipitated by experiences prior to becoming looked after, or whether the experience of being a looked after child engenders mental health difficulties (Stalker & McArthur, 2012).

### **4.2 Pathways to disabled children becoming looked after**

A range of complex factors lead to disabled children and young people becoming looked after, reflecting the same issues of neglect and abuse that feature for non-

disabled children placed in care (Baker, 2007). The research clearly indicates that disabled children are more vulnerable to abuse with a higher incidence of abuse reported amongst this population (Jones et al., 2012; Sullivan & Knutson, 2000; Paul & Cawson, 2002; Lightfoot et al., 2011; Stalker & McArthur, 2012). For example, Sullivan and Knutson (2000) reported on a total sample of 50,278 children and young people in one US state and found that disabled children were 3.4 times more likely than their non-disabled peers to experience abuse. Dependency on others for personal care, challenges in communication, lack of opportunity to alert others, and high turnover of care staff, are identified as factors rendering disabled children at greater risk of abuse (Paul & Cawson, 2002; Stalker & McArthur, 2012). These findings lead to concerns about the responsiveness of child protection procedures to the needs of disabled looked after children (Cooke & Standon, 2002; Stalker & McArthur, 2012) and concerns that disabled looked after children may be treated differently to their non-disabled peers as they are much more likely to be voluntarily accommodated in care rather than subject to a court order (Cousins, 2006; McConkey et al., 2004a).

In addition to issues relating to abuse or neglect, the capacity of families to continue to meet the care needs of their disabled child is an additional factor potentially contributing to placement in care (Llewellyn et al., 1999). This was a key feature in families who were caring for children with high level, complex care needs or challenging behaviours where parents report high levels of exhaustion and isolation, and concerns about managing challenging or aggressive behaviours and their impact on other children in the household (Benderix et al., 2007; Brown et al., 2011).

The literature also clearly indicates that families of disabled children are more likely to face external stresses, which may impact on their ability to continue to care, including poverty (Emerson & Hatton, 2007; Blackburn et al., 2010; Gordon et al., 2000), inadequate housing (Beresford & Oldman, 2002) and social exclusion (Akrami et al., 2005). This situation is often further exacerbated for families where there is a lone parent or more than one disabled child or adult living in the same household (Blackburn et al., 2010 in Read et al., 2012). In addition, Philips (2000) highlights the potential for family illness or the demands of parenting other children in the family as additional potential stressors for families of disabled children.

In this context, lack of early intervention and support for families with disabled children is identified in the literature as a factor contributing to families reaching a decision to seek an out-of-home placement for their child (Benedix et al., 2007; McConkey et al., 2004a; Nankervis et al., 2011). These findings emphasise the importance of investing in adequate, and in some cases intensive, supports for families of disabled children to enable parents to maintain their caring role alongside a good quality of family life for all family members.

### **4.3 Placement options for disabled looked after children**

The literature available indicates that disabled children and young people are more likely to live in congregate settings than non-disabled children and are less likely to be fostered (Burns, 2009). Older disabled young people and those with more complex or challenging needs are more likely to live in congregate residential settings (McConkey et al., 2004a).

Studies of foster care for disabled children emphasise the importance of training and a range of informal and formal support for carers and the disabled child in their care (Brown et al., 2005; Everson-Hock et al., 2011; Laan et al., 2001). Residential settings for disabled children and young people vary from specialist residential care in hospitals or schools to group homes or, for a minority, a secure unit (Burns, 2009). Although residential homes are regarded as a less popular placement option for children, Baker (2007) does report that they can provide a permanency option for disabled young people in long-term residential care.

Morris et al. (2002) examined residential schooling for disabled children in England and reported lack of clarity as to whether disabled children were subject to looked after child review processes or consulted about their placement experience and the extent of supports to facilitate contact with family and inclusion in the local community, given their distance from residential schools. Overall, however, there is limited research literature on disabled children's experiences of the range of residential care placement available. Similarly, although kinship care is an increasingly popular option for out-of-home placement for looked after children (O'Brien, 2012), no studies on kinship care for disabled children were available at the time of the literature review.

Short break placements are a popular service for disabled children and young people and their families. In these placements, disabled children spend time away from parental care either in a domiciliary arrangement in their own home or in an out-of-home stay in a family-based or residential setting. The reported benefits of short breaks include reduced carer stress and depression and improved family functioning which can facilitate enhanced care for the disabled child in the family home and reduce the need to seek out-of-home placements (McConkey et al., 2004b; Nankervis et al., 2011a). It is also important to note an emphasis on the importance of dual benefits of short breaks with positive social outcomes for the disabled child as well as a break from the caring role for their parent (McConkey et al., 2004b). Specialist short break placements combined with intensive family support have also been reported to have benefits for those presenting with severely challenging behaviour, enabling their families to continue to care for their child at home most of the time and offsetting crisis situations that may lead to longer term out-of-home placement (McConkey et al., 2011).

Despite the clear evidence of the benefits of a range of short break supports, the literature suggests that the availability of short break provision is insufficient to meet the demand for such services, particularly for children with multiple and complex care needs. For example, although families prefer small-scale, family-based breaks rather than larger congregate or hospital facilities, choice is often limited to what is available and demand exceeds supply (McConkey & Adams, 2000; Robinson et al., 2001). Further investment in short break provision for families in need and, in particular, those on the 'edge of care' may prove cost effective in the longer-term and reduce the need for out-of-home placements for disabled children and young people.

#### **4.4 Permanence for disabled looked after children**

Amongst disabled children there is a reported reduced likelihood that they will return to their birth family and, for those who do, this is more likely to happen after a longer period of being looked after (Baker, 2007). For children and young people who cannot continue to live with their birth families, outcomes are thought to be enhanced through the stability and security enabled through life in a permanent substitute family through adoption or long term kinship / non-relative fostering (Baker, 2007; Schofield et al., 2007; Fudge Schormans et al., 2006).

However, there is evidence that looked after disabled children are more likely to be placed in residential care. In addition, as disabled children are less likely to be adopted than their non-disabled peers (Baker, 2007), they are more likely to seek permanence with foster carers. However, long-term fostering is imbued with a sense of instability because of the lack of formal parental responsibility accorded to foster parents and the fostering arrangement may end when the child reaches the age of 18. Despite these legal insecurities associated with long-term foster care, the literature shows that disabled children can thrive in fostering environments, whilst also emphasising the importance of maintaining the relationship with the looked after young person's birth family, where appropriate (Baker, 2007; Fudge Schormans et al., 2006).

#### **4.5 Outcomes for disabled looked after children**

The literature indicates that broadly, looked after children experience negative trajectories in relation to health and educational outcomes (Crawford et al., 2006). There is a body of literature on mental health outcomes for looked after children, however, there is more limited research on outcomes for disabled looked after children.

Existing research suggests that educational as well as behavioural and emotional outcomes are likely to have a more negative trajectory for disabled looked after children than the already poor outcomes experienced by looked after children generally (Trout et al., 2009). In NI, Departmental statistics on educational outcomes

for looked after children show high rates of special educational need (SEN) (24%) (DHSSPSNI, 2010b). Of the 24% categorised as having SEN, almost half of them (48%) were reported to have a learning or severe learning disability and 12% were reported to have behavioural problems (DHSSPSNI, 2010b). Whilst this statistical data indicates additional educational needs for looked after children, there is a need to disaggregate the data to compare outcomes for disabled and non-disabled looked after children. Overall, the lack of outcomes-focused research is an important gap in the evidence in relation to disabled looked after children.

Many children and young people who live apart from their birth families in the public care system are vulnerable to developing emotional difficulties and mental ill health as a result of their pre-care, in-care and post care experiences (DeJong, 2010). Frequent changes of placement, feelings of loss engendered by separation from birth family and community; and lack of advocacy can all be factors in increasing vulnerability to developing mental health difficulties (Golding, 2010; Tarren-Sweeney, 2008). It is reported that children in residential care are more likely to develop mental ill health than those residing with foster carers (McNicholls et al., 2011; McAuley & Davis, 2009). Other factors that are reported to increase vulnerability include older age on entry to care and intellectual disability (Tarren-Sweeney, 2008). Given their exceptional vulnerability it is suggested that assessment of mental health should be undertaken on entry to care to facilitate diagnosis and access to specialist therapeutic support (Cousins et al., 2010; DeJong, 2010; Golding, 2010; Tarren-Sweeney, 2008).

#### **4.6 Disabled looked after children's perspectives**

There is a strong lobby from disabled young people and their advocates for the inclusion of the voice of disabled children and young people in research, policy and practice. However, much of the literature on disabled looked after children's experiences and needs has not sought the perspectives of disabled children and young people, often relying on professionals, parents or carers as proxies. Indeed, authors have noted the absence of the voices of disabled children and young people is a limitation of their research (McConkey et al., 2011).

Across the studies reviewed, it is also clear that younger children are less likely to be consulted (Davis & Wright, 2008) and those with mental health needs are more likely to be involved in research than those with other impairments (Blower et al., 2004; Mullan et al., 2012; Stanley, 2007). For example, Stanley (2007) sought the views of 14 looked after young people in two English local authorities concerning their mental health needs and found that young people highlighted the negative impact of disruption within the looked after system on mental wellbeing and preferred counsellors who had prior experience of being in care themselves.

The value of consulting with disabled looked after children and young people about their experiences is highlighted by many authors in terms of enabling the empowerment of young people who traditionally have been excluded from research and providing unique information on their experiences to inform service planning evaluation (Kelly, 2007; Mullan et al., 2012). These findings indicate that researchers studying out-of-home care provision need to adopt more inclusive and participatory approaches that will help to address the notable gap in knowledge of the perspectives and experiences of disabled children.

#### **4.7 Summary**

The existing evidence base provides some insight into the experiences disabled looked after children but also highlights gaps in knowledge that require the attention of future research. The literature reports on difficulties in establishing the prevalence of disability in the looked after child population. Accurate, clearly agreed definitions of disability across jurisdictions and services may enable more rigorous empirical investigation of the profile of this population.

Whilst it is difficult to estimate the prevalence of disabled looked after children, there are some indicators as to the population characteristics. A high proportion of the looked after child population experience mental health difficulties. In addition, it is reported 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 form a greater proportion of the population than other types of impairment.

Disabled children become looked after for many of the same range of pre-care reasons as their non-disabled peers and are deemed to be at greater risk of neglect, abuse and violence than non-disabled children. However, disabled looked after children are more likely to be voluntarily accommodated than subject to a care order. This legal status may reflect the challenges of accessing adequate practical and emotional supports to meet the needs of parents of disabled children and enable them to continue to provide care for their disabled child at home.

Additionally, there are indications in the literature that outcomes for disabled looked after children require further attention in relation to education as well as their emotional wellbeing. There is a high incidence of mental health difficulties in this population and a clear need for targeted support and intervention.

With regard to the views of disabled children and young people, the research highlights that whilst birth parents, carers and professionals are common respondents in research, there are limited examples of research incorporating the voice of disabled children or young people.

### ***Key Messages***

The review of literature has highlighted particular gaps in knowledge and identified the following priority areas for future research, policy and practice.

- Accurate, clearly agreed definitions of disability across jurisdictions and services would enable the collection of integrated data on disabled looked after children that would enable population-based studies and inform service planning and development.
- Further research could examine differential child protection responses for disabled children in comparison to their non-disabled peers, including legal status on entry into care.
- Practical and emotional supports for parents of disabled children, including short breaks, help to prevent family breakdown and reduce the need to seek alternative care placements. Timely access to a greater range of short break provision is recommended to support parents of children 'on the edge' of care to maintain their caring role and prevent admission to care.
- The mental health of children and young people should be assessed on entry to the care system to ensure appropriate diagnosis and therapeutic intervention.
- Further outcomes-focused research should be undertaken to examine pathways and outcomes for disabled looked after children across domains of health, behaviour and education.
- A review of care placements provided for disabled looked after children should be undertaken to ensure equal opportunities for family-based care and permanency.
- Future research in this area should incorporate participatory studies ascertaining the views and perspectives of disabled looked after children. In addition, disabled looked after children should be involved in decisions relating to their care and in the development of policy and practice aimed at improving outcomes for disabled looked after children.

## **5.0 METHODOLOGY**

This is a two-stage, multi-method study which aimed to examine the population of disabled children in care in NI, profiling their numbers and characteristics and investigating their care experiences.

### ***The research objectives were to:***

- Examine the characteristics of disabled children young people living in public care.
- Identify the key factors that lead to disabled children and young people becoming looked after.
- Examine the organisational arrangements and procedures within Trusts impacting on services for disabled children and young people who are looked after.
- Investigate the experiences of disabled children and young people who are looked after, 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 who are looked after.

The approach to data collection and analysis was guided by a Professional Advisory Group and a Young Person's Steering Committee. As part of the process of negotiating access to staff in HSCTs to undertake the survey, a Local Collaborator at senior management level was identified in each HSCT to join the Professional Advisory Group. These individuals also provided a key communication link with the Trusts, helping to facilitate the collection of data from individual social workers. Prior to the commencement of data collection, ethical approval was given by ORECNI and approval was granted by each of the five HSCTs.

Following the review of the policy context and existing literature on the needs and experiences of disabled children and young people in care, the study had two key stages of data collection: (1) a survey providing demographic data on the population of disabled LAC in NI; and (2) case studies of a sample of this population involving reading case files and interviews with children and young people, carers, birth parents and social workers.

### **5.1 Inclusion criteria**

Disabled children and young people included in the study were required to meet the following definitions of 'disabled' and 'looked after':

- **The definition of disability** used in this report is that outlined in the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006:4): “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” In accordance with this definition, looked after children were included in the study if there were assessed as:
  - Having a cognitive, physical or sensory impairment; and/or
  - Having a mental illness or either awaiting/receiving mental health services; and/or
  - Being on the autistic spectrum; and/or
  - Meeting the threshold for receiving services from a children’s disability team.
- **A child or young person is fully looked after** if s/he is:
  - Living in public care due to a court order/being voluntarily accommodated for more than 24 hours (Children (Northern Ireland) Order 1995), usually in residential homes/schools, foster care, kinship care or hospital facilities;
- **A child or young person is looked after due to short break usage** if s/he:
  - uses short breaks for a period of more than 24 hours (a short break placement should not exceed four weeks and the total time spent in short breaks should not exceed 90 days in one year). As many disabled children are looked after due to short stays in short breaks, for the purposes of the study, we only included those who had short break stays exceeding 35 days in one year or a continuous period of 28+ consecutive days in one year.

Any child or young person meeting the above disability criteria who was looked after at any time from 30 September 2012 to 30 September 2013 was included in the study. This time period for data collection fitted with the timeframe for the study. The end date for data collection also corresponded with the date for the last DSF return in 2013 (at 30 September 2013) to help social workers identify relevant cases for inclusion in the study and allow for some comparison of findings for disabled LAC.

## 5.2 The survey approach

Data was collected using a structured questionnaire completed by social workers online or in hard copy for all children and young people on their caseloads who met the study's inclusion criteria. The questionnaire requested information about the child’s family background, reasons for being looked after, looked after status, length of time in care, placement type and stability, and birth family contact arrangements. Information was also collected about school experiences, risk taking behaviour, additional needs and contact with other services. For those children using short

breaks, a section gathered information about the length of time using the service, the type of placement, placement changes and extent of short break usage.

In order to maximise the response rate, it was necessary to work closely with the full range of social work teams working with these children across the five HSCTs (across disability, mental health and child care teams). Meetings were held with relevant senior managers, followed by team leaders and social workers to ensure they were fully informed about the research and survey approach. In each Trust, the researcher undertook demonstrations of the online survey to illustrate how to complete it and ensure the inclusion criteria and questions were clearly understood.

Through this process each social worker identified the number of children on their caseloads who met the study inclusion criteria and for whom they would be completing a questionnaire which enabled the researcher to follow up on lower than expected responses from individual social workers. Before leaving the team, a timescale for completion of the questionnaires was agreed (usually two weeks). When the agreed time scale lapsed, the researcher checked the number of returns on the online system and followed up with individual social workers on any missing data or lower than expected returns.

### **Survey response**

Our total sample is 487 disabled LAC with 164 who were LAC solely due to short break usage and the remaining number of fully LAC (n=323) representing 11.2% of the overall LAC population at 30 September 2013 (n=2892) as reported in the DSF report (HSCB, 2013). This corresponds to the number of disabled LAC recorded in the DSF report (n= 333 or 12% of the overall LAC population). These figures can be compared with those for the general child population in NI (0-18 year olds) where 7% of children are disabled<sup>2</sup> (although census data was collected at an earlier time period) (NISRA, 2011), indicating that disabled children are over-represented in the fully LAC population in NI.

The overall sample includes children and young people with physical, sensory, mental and intellectual disabilities, and those on the autistic spectrum. The highest number of returns were received from the SEHSCT (n=117); followed by the WHSCT (n=107) and BHSCT (n=105), with lower responses from both the SHSCT and NHSCT (both n=79). There was also variation in the numbers of disabled fully LAC in the study sample across the five Trusts. The highest numbers were in the SEHSCT (n=92) and BHSCT (n=90), followed by the NHSCT (n=59), the SHSCT (n=45) and the WHSCT (n=37). Such prevalence trends may reflect lower response rates in the

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<sup>2</sup> Taken from taken from the most recent NI census data statistics on children with: 'learning, intellectual, behavioural or social' conditions; 'emotional, psychological or mental health' conditions; 'deafness or partial hearing loss'; 'blindness or partial sight loss'; and 'mobility or dexterity difficulty'.

NHSCT and SHSCT and differing service structures in the remaining Trusts, for example, increased availability of preventive services such as residential short break services in some Trusts.

### **5.3 The case study approach**

The qualitative aspect of the study used a case study design 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.

#### ***Sampling***

A total of 15 disabled children and young people were recruited to take part in the case studies using the sampling frame developed as part of the survey stage of the project. 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. Further details on the characteristics of the children and young people who participated in the case studies are available in the full report (Kelly et al., 2016).

#### ***Negotiating access***

Following selection from the sampling frame, each selected child's named field social worker was contacted to: ascertain if their birth parents were contactable to give consent for their child to participate; and to determine if the child might be adversely affected by participating in the study. For a number of children, consent was not progressed because birth parents could not be contacted or there was concern about the child's wellbeing. For example, some children were in the process of a placement breakdown, family crisis or court action. Others had experienced a recent bereavement, or were hospitalised due to ill health. In cases where consent processes could not be progressed, replacement cases were re-sampled using the survey sampling frame.

### ***Recruitment and consent***

A range of sources of information about the study was provided for potential participants. Separate information leaflets were prepared for social workers, carers and parents. An easy read 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 with images and easy read text were made available. In addition, a DVD was developed in partnership with disabled young people from the Barnardo's Sixth Sense group to share information about the study with potential participants.

Social workers were asked to share information about the study with birth parents sharing parental responsibility and ask for consent to the child's participation, as well as consent to their own participation. 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, field social worker consent was sufficient. 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 approached the child to ask for their agreement to participate. Two children decided not to participate because they did not identify with being in care or being disabled. Once children and young people agreed to take part, we then asked the child's main carer (foster/kinship carer) and field social worker for consent to their own interviews as part of the case study.

### ***Case file reading***

Following recruitment to the study, the first task was to read the child's social work case file and record anonymised information on the child's experience of: impairment, education, coming into care, placement experience and change, legal status and use of services. Case files were read in social work offices and, in some instances, repeat visits 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.

### ***Case study interviews***

A series of semi-structured interviews were arranged on completion of case file reading. Children, birth parents and carers were met in their home environments.

Social workers were usually interviewed at their place of work. Finally, interviews were conducted with senior managers of children’s disability services and looked after child services in each of the HSCTs. 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.

<b>RESPONDENT</b>	<b>NO. OF INTERVIEWS</b>
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
<b>TOTAL NO. OF INTERVIEWS</b>	<b>63</b>

Table 1: 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. All interviews were audio recorded with prior consent and transcribed for analysis.

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).

#### **5.4 Data analysis**

Before survey data analysis commenced, the researcher undertook necessary data cleansing. This process involved sorting labelling systems and collapsing variables, where appropriate, to facilitate data analysis. Data analysis began by running frequencies and cross-tabulations to identify findings across the full range of questions and possible responses. For the purposes of analysis, the database was then split in two for those who were disabled fully LAC and those who were short break LAC as the experience of these two groups was distinct. Relationships between different sub-groups of disabled LAC were identified by conducting cross-tabulation of combinations of variables; for example, impairment and placement type.

All transcribed interview 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).

#### **5.5 Study limitations**

Although every effort was made to ensure completion of surveys, it is possible that some social workers did not complete surveys for children who met the study criteria. It is not possible, therefore, to claim that the sample represents a full census of all disabled LAC in NI. However, a substantial response to the questionnaire was achieved indicating a strong response rate matching the prevalence of disability recorded in the DSF return for the same period (12%).

Given the need to re-sample cases where consent could not be progressed, it is possible that disabled children and young people facing the most significant challenges during their time in care were not included as case studies. It was necessary to approach the qualitative phase of the study in a sensitive and ethical manner, respecting the judgement of professionals and those holding parental responsibility with regard to the potential to cause harm or distress to the child. However, as the sample of children recruited did represent a range of experiences, some with current challenging issues, the research team are confident that children

with both positive and negative experiences of the care system have been selected as case studies. It must be acknowledged, however, that there may have been some cases where adult gatekeepers prevented the inclusion of children who may have agreed to take part if the researcher had an opportunity to approach them directly.

Finally, it is important to note that the study required an extension of time to allow for delays in return of surveys and additional time necessary for the complex consent process required to achieve the case study sample. With a more straightforward consent process, a larger case study sample could have been recruited. However, the case study phase of the project did not seek a representative sample of the population and was successful in capturing rich data on the experiences of disabled looked after children and their parents/carers.

### **5.6 Summary**

A two-stage, multi-method study design was adopted to address the research questions, incorporating qualitative and quantitative approaches. The study began with a review of the policy context and existing body of literature, followed by a profiling survey completed by social workers for disabled looked after children across NI. A total of 15 case studies were then conducted to explore the views and experiences of disabled looked after children and examine the perspectives of their birth parents, carers and social workers.

The fieldwork process took considerable time to maximise the survey response rate and allow time for the complex process of recruiting disabled looked after children and completing case file reading and interviews with a range of respondents. It was important to dedicate this additional time and effort as this is the first study to capture the profile of the population of disabled children in out-of-home care in NI and to ascertain the views and experiences of disabled children living in out-of-home care and those of their significant caregivers.

## **6.0 THE PROFILE OF DISABLED CHILDREN IN OUT-OF-HOME CARE**

This section of the summary report gives an overview of the profile of the two distinct groups of disabled children in out-of-home care: those who are fully looked after (in full-time care of the state) and those who were looked after due to short break usage.

### **6.1 The Profile of Fully Looked After Disabled Children**

This section provides an overview of the profile of fully looked after disabled children and young people, including the: prevalence of disability and additional needs; family background; legal status; education; short break usage ongoing risk; and access to support services.

#### **6.1.1 Prevalence of disability**

A total of 323 disabled children and young people in our sample were fully looked after. This represents 11.2% of the total looked after population in the same period. Comparative figures from NISRA (2011) show that 7% of the general child population (0-18 year olds) are disabled, demonstrating an over-representation of disabled children in the looked after population in NI.

The two main sole impairment types were intellectual disability (27%) and mental health (27%), representing over half of the study sample. There was also a high incidence of co-existing impairments (39%).

Those with an intellectual disability, physical disability, co-existing intellectual disability and ASD or multiple impairments were more likely to have their impairment identified before they came into care. In contrast, those solely with ASD or mental health needs were more likely to have their impairment identified after becoming LAC.

Overall males (58%) were more numerous than females (42%). The higher number of males applied across all impairment groups with the exception of the sole mental health category where there were more females (58%). There were notably more males in the intellectual disability categories: 61% of those with a sole intellectual disability were male and all of those with co-existing ASD and intellectual disability were male.

The profile of fully looked after disabled children and young people who revealed 'additional needs'. According to social workers 53% were profiled as having challenging behaviours, 23% with speech and language disorders, 21% with ADHD/ADD and 16% with anxiety.

The numbers of fully looked after disabled children and young people grew as they aged. Mental health need was most commonly present in the 16+ age group for both genders. This is in comparison with the general looked after population where there are substantially more younger children and a decline in numbers of young people aged 12 years and over (HSCB, 2013).

### **6.1.2 Family background**

More than half (60%) of fully looked after disabled children and young people came from a single parent household. From the information available on parents, a quarter of mothers had a history of being in out-of-home care, with 16% of mothers and 8% of fathers reported to have an intellectual disability. Almost half of the sample were reported to have one parent with a mental health need.

Over a third (36%) had siblings who were not in out-of-home care, most commonly those with co-existing intellectual disability, ASD or mental health need.

Those children whose siblings were also looked after were more than twice as likely to live apart from their brother or sister as they were to reside in the same placement.

### **6.1.3 Legal status**

The majority of fully looked after disabled children and young people were under a Care Order (66%) (this compares with 54% of the general looked after population). A further 23% were voluntarily accommodated compared with 28% in the general looked after population. Older males with an intellectual disability, ASD or mental health needs were more likely to be voluntarily accommodated.

The majority had been in out-of-home care for more than five years (39%), followed by 3-5 years (25%) and 1-2 years (23%). The general looked after child population differed in that there were lower numbers spending three years or more in care and a higher number in care for less than 12 months (27% compared with 12% of the study sample).

### **6.1.4 Reasons for entry to care**

Neglect was the most common reason (70%) for disabled children becoming fully looked after, often in combination with emotional abuse and parents not coping (both 53%). One third had witnessed domestic violence and just over a quarter had been subject to physical abuse (27%), with 19% reported to be beyond parental control. A smaller proportion (9%) had experienced sexual abuse, mostly teenage females.

Almost three quarters (74%) had been subject to a child protection investigation and case conference prior to entry to care; with 70% being placed on the child protection

register. However, in contrast with the general population (8%), a fifth of the study sample were on the child protection register whilst in care. Half of those at home on a Care Order were on the child protection register and 38% of those in specialist foster care. Of those on the child protection register whilst in care, 40% were reported to present with risky sexual behaviour, 33% with risk of suicide and 36% with risk of substance misuse.

The two main age groups for those brought to case conference/registered whilst in care were 4-11 years and 16+ years; with mental health being the dominant impairment category. In the 4-11 age group, males were most likely to be subject to a case conference and registration whilst in care; a trend reversed for the 16+ age range.

### **6.1.5 Ongoing risk**

Overall, 39% of fully looked after disabled children and young people were reported to be engaged in risky sexual behaviour, 28% at risk of attempted suicide and 27% engaged in substance misuse.

Those with mental health needs and those in the 16+ age group were at highest risk across all risk categories. Females were reported to be at highest levels of risky sexual behaviour and risk of suicide.

Almost a fifth (19%) had received a police caution and 11% a criminal conviction. These figures are much lower in the general looked after population (3% cautioned and almost 2% convicted). All criminal convictions and the majority of police cautions (74%) occurred after young people had come into care.

Of those with a police caution, 81% were in the 16+ age category; and almost all of those convicted were in the 16+ age category. Those with mental health needs and/or ASD were more likely than others to have a caution or criminal conviction. Males were also more prevalent, most notably in conviction rates, with two thirds of those with convictions being male.

### **6.1.6 Placement type**

Similar numbers of fully looked after disabled children and young people were in non-relative foster care (40%) as those in the general looked after population (39%).

However, much lower levels of kinship care were reported for disabled children and young people (17%) compared with the general looked after population (32%). In addition, only 5% of disabled children and young people were placed at home compared with 12% for general looked after population.

In contrast, fully looked after disabled children and young people were more than twice as likely to be living in residential care (children's residential home or a specialist residential care) (17%), compared with the wider looked after population (7%). In addition, 14 fully looked after disabled children and young people were placed out of area in a specialist residential placement (including three young people placed outside NI). These were mostly older males with an intellectual disability/ASD who often also presented with challenging behaviours.

### **6.1.7 Placement changes**

Fully looked after disabled children and young people were more likely to experience placement instability than the general looked after population. Over three quarters of the general looked after population had no placement changes compared with just over a third (35%) of looked after disabled children and young people. In relation to the number of placement changes for looked after disabled children and young people:

- over one third (34%) had been subject to 1-2 placement changes compared with 12% of the general looked after population;
- 29% had experienced 3+ placement changes, compared with 12% of the general looked after population; and
- 9% had moved six or more times, including 10 young people (3%) who had more than 10 placement moves.

Whilst placement change was generally linked with older children and those who had been in care for some time, there was also evidence of significant disruption for younger children and those in care for shorter periods. Children with mental health needs including those with co-existing impairments experienced greater placement instability.

### **6.1.8 Contact with family**

Almost two thirds (63%) of fully looked after disabled children and young people had regular planned contact with their birth mother and just over one third (35%) with their birth father. A fifth had irregular contact with their birth mother and a further 17% had no contact at all. Whilst 19% had irregular contact with their birth father, 44% had no paternal contact.

Almost two thirds (62%) had regular sibling contact whilst 10% had no contact with siblings. Over a quarter (27%) remained in regular contact with grandparents whilst just over half (53%) had no grandparent contact.

### **6.1.9 Use of short breaks among fully looked after disabled children**

Of those who were fully looked after, 32% also availed of short breaks across impairment types, mostly those living in non-relative foster care (51%) followed by kinship foster care (19%).

Few children in the youngest age group used short breaks (3%), with the highest usage found amongst those who were in the 12-15 age group (38%), followed by those aged 4-11 years (31%). Almost twice as many males (63%) as females (37%) used short breaks.

The majority of short break placements were in non-relative foster settings (28%) or specialist residential settings (21%). Overall, the use of short break stays was low, with only one young person exceeding 35 days of short breaks. Similarly, although non-residential short break options such as domiciliary care were available, only 4% were reported to have a domiciliary carer.

Short breaks were most commonly used as a support for the child's carer or placement rather than being viewed as a social opportunity for the child.

### **6.1.10 Education**

Overall, 64% of fully looked after disabled children were reported to have a Statement of Special Educational Need (SEN), compared with 26% in the general looked after population (DHSSPSNI, 2015). The majority of these had ASD and/or intellectual disability or multiple impairments. Only 14% of those solely with mental health needs were identified as having a SEN.

Those attending special units within mainstream schools (8%) mostly had an intellectual disability or ASD. Amongst those attending a 'special school' (34%), the majority had an intellectual disability or multiple impairments. A small number of children with an intellectual disability or ASD attended a residential school.

More than a third (38%) had between 1-2 school changes, 8% had 3-5 school changes and two young people have more than six school changes. School change was more likely for those in mainstream schools and those with mental health needs and/or ASD. All of those in the NEET category (8%) were in the 16+ age range and mostly had mental health needs.

### **6.1.11 Access to support services**

A quarter of fully looked after disabled children and young people had access to Tier 3/4 CAMHS and 23% accessed LAC Specialist Therapeutic Services. There is some indication that those with intellectual disabilities had lower levels of access to these specialist mental health/therapeutic services. For example, only 28% of those with co-existing mental health and intellectual disability accessed Tier 3/4 CAMHS

compared with 57% of those solely with a mental health need. Similarly, only 3% of those solely with an intellectual disability, accessed LAC specialist therapeutic services.

Fully looked after disabled children and young people accessed a range of other professionals including community paediatricians (41%), health visitors (35%), speech and language therapy (29%), occupational therapy (26%) and hospital specialists (25%). The majority of those accessing these services had multiple impairments or intellectual disabilities.

Although 37% of the total sample were aged 16+ and 31% were in the 12-15 age range, low levels of engagement with transition services were reported with only 14 (4%) accessing a transition co-ordinator. However a quarter of the sample were accessing 16+ social work services and 18% were engaged with a personal advisor (mostly those with mental health needs).

Only 10% of disabled children and young people who were fully looked after were accessing either an independent visitor or an independent advocate indicating a low levels of independent support and advocacy provision for this group of children and young people.

## **6.2 The Profile of Disabled Children Looked After Due to Short Breaks**

This section provides an overview of the profile of disabled children and young people looked after due to short break usage, including the: prevalence of disability and additional needs; family background; legal status; education; short break usage ongoing risk; and access to support services.

### **6.2.1 Prevalence of disability**

A total of 164 disabled children and young people were looked after solely due to short break usage for more than 35 days in one year or more than 29 consecutive days in one year. Just over two thirds (67%) were male and most were in the older age ranges (aged 12+).

All but one of the children and young people in this sample were reported to have an intellectual disability and for the majority this was categorised as 'severe'. However, many of these children had a co-existing impairment (34%) or multiple impairments (47%). There were 35 wheelchair users (all placed in residential short break settings) and a large majority (94%) required assistance with personal care needs. These findings highlight the complexity of need within the short break LAC group

Those in the short break LAC group who also had mental health needs were most likely to access support through consultant psychiatry within learning disability services. Only 4% had access to CAMHS and none were receiving LAC therapeutic services.

Relatively high levels of additional health needs were identified for short break LAC, particularly speech and language disorders (60%) and challenging behaviours (57%). More than a fifth were also reported to have epilepsy, enuresis or ADHD/ADD.

### **6.2.2 Family background**

The majority (61%) of short break LAC came from a two parent family, with 39% living in a single parent household. This is in contrast to the population of fully looked after disabled children and young people where almost two thirds came from a single parent household.

Few parents of short break LAC were identified as having an impairment (9%), compared with 16% of mothers and 8% of father in the fully looked after sample. However, more than a fifth (22%) of parents of short break LAC had mental health needs (compared with almost half of the fully looked after group), often accessing higher levels of short break support.

Only 13% of short break LAC had siblings who were also looked after. For those siblings who also used short breaks, these were most often in the same short break placement.

### **6.2.3 Short break type**

The large majority of short break LAC (92%) were placed in a specialist short break residential facility. Very few were placed in foster placements as a short break placement which is in stark contrast to the fully looked after group who were more likely to have short breaks with foster carers than in residential settings. This over-reliance on residential placements may reflect the lack of specialist foster care placements available to meet the more complex care needs of these children and young people.

### **6.2.4 Short break usage**

Two thirds of short break LAC accessed between 35-50 days of short break per year. A further 15% received between 51-65 short break stays. Only 10 children were reported to have a higher allocation and these were much more likely to be male and in the older age range. In terms of impairment type, all those using higher numbers of short breaks (66-90) had an intellectual disability which co-existed with ASD in all but one case.

Four young people (aged 12+ and all but one male) exceeded the 90 day rule having in excess of 90 days of short breaks in a one year period. One of these young people had multiple impairments and epilepsy; the remaining three presented with co-existing ASD, severe intellectual disability and severely challenging behaviours. One of these young people had also been in a single short break placement for more than 28 days.

In the large majority of cases (96%), the most commonly cited reason for short break usage was a planned break for the carer. However, in 68% cases, the short break was also regarded as a social opportunity for the child. Only 9% of short breaks were in response to a crisis, however, 12% of short breaks were to prevent the child becoming fully looked after.

### **6.2.5 Short break placement change**

The short break LAC population had significant experience of using short break services. More than half had been using short breaks for more than three years, with many of these exceeding five years of short break experience. In addition, short break provision was a stable service with only 11% experiencing placement changes.

### **6.2.6 Education**

All of the short break LAC had a Statement of Special Educational Need (SEN) and the large majority (94%) attended a special school. Only seven children experienced school changes, with only 1-2 changes in special schools or a unit within mainstream schools. There were no school changes amongst the short break LAC population attending mainstream school.

### **6.2.7 Safeguarding and risk**

Overall, 13% of short break LAC were subject to child protection proceedings before they availed of short breaks, with 9% being placed on the child protection register. Similarly, 11% were subject to child protection proceedings whilst short break LAC, with 6% registered. Although these are relatively small numbers overall, they do highlight ongoing child protection concerns amongst the short break LAC group with a less marked reduction in child protection concerns before and after becoming looked after compared with the fully LAC sample. Reflecting the demographic of the short break LAC sample, those subject to child protection proceedings were more likely to be older males with multiple impairments or co-existing intellectual disability and ASD.

In contrast with the fully looked after group, there is limited evidence of risky behaviour amongst short break LAC. In addition, only one young person had received a police caution and none had been convicted. High levels of surveillance

of young people with intellectual disabilities or multiple impairments both in residential units and within their home and school life, alongside limited opportunities for independence, are likely to mediate against criminal activity.

### **6.2.8 Access to services**

The short break LAC group accessed a high level of additional support through a range of professionals in comparison with the fully looked after group, with the exception of health visiting services. For example, 73% accessed a community paediatrician, compared with 41% of the fully looked after group; 58% accessed speech and language therapy compared with 29% of the fully looked after group; and 53% accessed occupational therapy compared with 26% of the fully looked after group. This increased access to services may be expected given the more complex needs of short break LAC, however, they may also reflect the provision of some of these services within special schools as a high proportion of short break LAC attended special schools.

Very low levels of access to mental health services were reported, however, 54% of this sample had input from psychiatry, mainly from learning disability service sector.

It is also important to note that almost one fifth of short break LAC were also accessing additional supports indicating that their families had access to support from a range of short break services.

Whilst 22% of this study sample had access to a transition coordinator, this figure is low given that 81% were aged 12+ years. In addition, although more than a third of short break LAC were aged 16+, none had access to a 16+ social worker, personal advisor or employment officer. These findings indicate a lack of transition planning and support for short break LAC and may reflect barriers in access to leaving care services and/or slower transitions for the short break LAC sample. Similarly, there was a gap in independent advocacy and support for this study sample.

### **6.3 Summary**

Disabled children and young people continue to be over-represented in the care system in NI. A total of 323 disabled children were in full-time out-of-home care which represents 11.2% of the total LAC population in the same period, compared with only 7% of the general child population in NI being disabled.

In the fully looked after group, the two dominant impairment types were intellectual disability and mental health, followed by those with multiple impairments. Those with ASD and/or mental health needs were much more likely to have their impairments identified after coming into care. Almost all of the short break LAC had an intellectual disability, with many reported to have additional health needs and challenging behaviours.

In both 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. In the fully looked after group, the numbers increase with age with the highest number being in the 16+ age group. This contrasts with the general LAC population and short break group where numbers decrease in the 16+ age group.

A higher proportion of the fully looked after group were subject to child protection proceedings prior to coming into care compared to the short break group. Those in full-time care were most commonly living in foster care and less likely to be living in kinship care or placed at home than the general LAC population. Those in the short break group mostly stayed in residential settings, indicating a lack of specialist family-based short break care. Placement instability, school change and vulnerability to risk-taking behaviours was more marked for the fully looked after group in comparison to short break LAC, particularly for those with mental health needs.

Short break usage amongst the fully looked after group was aimed at providing a breaks for carers. Those in the short break group were more likely to report this service was also provided as a social opportunity for the child.

Across both groups, lack of access to specialist mental health services was reported, with those with co-existing impairments often relying on learning disability services to meet mental health needs. Despite the high numbers in the older age range, lack of access to transition supports was also evident across both groups.

## **7.0 THE NEEDS AND EXPERIENCES OF FULLY LOOKED AFTER DISABLED CHILDREN**

This section of the summary report provides an overview of the views and perspectives of looked after disabled children and young people as well as the views of their birth parents, carers and social workers. As indicated, the findings reported are based on interviews with a sample of 15 fully looked after disabled children and young people; 13 birth parents; 9 foster carers; 2 residential key workers; 14 social workers; and 10 social work managers. The case files of the 15 disabled children and young people were also read.

### **7.1 Reasons for entry to care**

Social workers, parents and carers identified a complex and inter-related set of factors that could lead to the entry of a disabled child into care. These include: parental factors (including poor adjustment, limited access to personal, economic and social resources); child factors (including high level needs and challenging behaviours) and child abuse and neglect.

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.

The majority of children and young people in the case study sample had been engaged with child protection services and placed on the child protection register prior to entry to care. Two other young people were subject to child protection investigations but not placed on the register as they were taken into care. Two young people were not subject to child protection procedures as they were voluntarily placed in care and there were no child protection concerns.

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. Several children were voluntarily placed in care often due to a breakdown in parental capacity in the context of their child's complex or multiple needs or challenging behaviours, particularly where there were other stressors such as siblings, single parenthood and parental illness.

In addition, several 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. Other challenges for parents included chronic fatigue, financial hardship and social isolation. Cumulatively, with combinations of these challenges over time, parenting can be under intolerable pressure and become compromised, leading to the heightened vulnerability of disabled children to abuse, neglect or relinquishment into care.

Social workers and managers reflected on the challenges of responding to concerns about parental capacity or neglect when parents were under immense strain linked to their caring role and there is an emphasis on keeping families together with the provision of additional support services. This highlights a concern that there could be occasions when an over-emphasis on supporting stressed parents occurs at the expense of early detection and decisive responses to concerns about abuse or neglect. 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.

Understanding the effects of impairment on children and young people was a key aspect of supporting disabled children and young people. In one case, a young person with undiagnosed ASD was admitted to care due to violent behaviour in the home. This young person was later diagnosed with ASD and both she and her birth parent believed an earlier diagnosis and access to specialist services may have prevented a deterioration in behaviour and avoided her admission to care. Similarly, in other cases, parents emphasised the importance of early diagnosis and intervention and need for further access to support within the home. Social workers and 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.

During interviews with parents there was much reflection on the reasons for their child's entry to care, with each story being individual. Some parents were unclear and uninformed about the reasons for the entry of their disabled child into care and disputed the basis of those decisions. Others were clear about their own limitations explaining that they lacked the skills and resources required to care for their disabled child, particularly if they were premature or had specific health needs.

Several parents whose children were removed following child protection concerns (often in the context of parental alcohol/substance misuse), described the admission of their child into care as a critical point in their lives that led to a turnaround in their personal lives that later, with support, enabled them to have their child returned to their care.

## **7.2 Coming into care**

Children expressed a variety of views about coming into care. Some had only vague memories of their family life while others had vivid memories and wished things had turned out differently. Some felt confused and shocked.

Carers also expressed their perspectives. Kinship carers generally commented that the process had gone well, given their established relationships with the child in their care. Some non-relative foster carers felt that they needed more information regarding the disabled child coming into their care.

Parents also talked about their memories of when their children were taken into care and their interaction with social services at the time. Some parents felt that social services had not listened to their views on the needs of their child or family presenting issues and did not work in partnership with their family.

## **7.3 Perspectives on legal status**

The interviews revealed that the presence or absence of legal orders can cause confusion for carers and parents. Some foster carers found day-to-day decision making regarding aspects of the care of the disabled child who was voluntarily accommodated challenging because they did not have legal parental responsibility.

Some birth parents whose disabled child was the subject of a Care Order felt routinely included whilst others felt increasingly left out of decisions as time passed. Indeed, one parent was uncertain about her parental rights in relation to her disabled child's life and asked the researcher for clarification.

Social workers and managers also found certain aspects of the looked after status challenging. For example, managing the implications of caring for a voluntarily accommodated child who theoretically could leave care at any time. However, one benefit of being voluntarily accommodated was the ongoing close involvement of parents during their child's time in care.

The categorisation of disabled children and young people as looked after on the basis of accessing short breaks caused concerns for parents and social workers. Most found this statutory process unnecessary and felt that the review of short break arrangements could be undertaken as part of family support processes.

Social workers also raised concerns relating to disabled children making extensive use of multiple short breaks 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 was a view that they actually required a formal shared care arrangement. On the other hand, social workers and managers reported a sense of frustration with inflexible regulations regarding the '90-day rule' which prohibited

longer stays in residential short break placements and highlighted the need for such a high level of support in some cases.

#### **7.4 Experience of placement type**

Disabled children and young people lived in a variety of settings including kinship care, non-relative foster care, residential homes and other specialist settings including hospitals and specialist community settings.

Although social workers reported lower numbers of extended families taking on the full time care of a disabled child removed from their birth parents, these placements were positively appraised by respondents. Children and young people in kinship care placements experienced much more placement stability 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.

Birth parents and carers also reported positive experiences of kinship care and emphasised the importance of advice and support to assist kinship carers with their caring roles. Some carers and social workers also highlighted the need for kinship care placements to be subject to more regular review processes.

All of the children living in non-relative foster care spoke positively about their placements. Similarly, most parents were happy with their child's non-relative foster placement but some expressed concerns about communication with carers and the impact of multiple placement changes on their child.

The main issues in relation to non-relative foster care were lack of availability, placement instability and lack of adequate support for carers. There was a tendency to rely on short-term carers to provide longer-term placements. In addition, foster placements were often sought through private fostering agencies but these were often out of Trust area. Despite these concerns, social workers were overwhelmingly positive about the quality of care provided by non-relative foster carers. Social workers emphasised the value of carers with previous carer experience or knowledge of disability issues.

There was a general view from all respondents that mainstream residential homes were not well configured to meet the needs of disabled young people, particularly those with mental health needs and those on the autistic spectrum. In addition, there were concerns about the increased vulnerability of disabled young people in mainstream residential homes to bullying, manipulation and risk-taking behaviours.

Therapeutic and specialist residential care was positively appraised, particularly for disabled young people presenting with very challenging behaviours, severe mental health disorders or high levels of risk to themselves or others. However, the absence of a range of specialist residential care was noted, with social workers reporting an increasing number of cases where placements outside NI were sought. While noting the financial and practical difficulties associated with out-of-area placements, social workers and parents spoke very highly 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.

### **7.5 Permanency planning**

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, with most feeling powerless in relation to these multiple moves. Placement change was often linked to an emergency crisis or repeated breakdown of short-term placements as social services struggled to find an appropriate, long-term placement for the child. These findings highlight the importance of permanency planning for disabled children in out-of-home care.

Permanency planning can include return home, long-term foster or specialist residential care, adoption and transition to adult services. For those disabled children and young people who returned home, delay was sometimes noted with interviews revealing that timely decision making was important. Ongoing partnership-based relationships between parents and social services was also very important as was the provision of ongoing practical support through short breaks. However, not all disabled children, on return home, wanted to avail of these short breaks.

For a small number of disabled children adoption had been the permanency plan. However, interviews highlighted the difficulties sourcing adoptive placements for disabled children.

Some disabled children remained in long-term foster care. For some foster carers and disabled children this worked well as 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. For others, concerns about their ongoing ability to care for disabled children was emphasised, given the strain of the caring role on other family members and themselves as they aged. Disabled children in these situations were often unaware that their placements were unstable. 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.

Carers who had access to short breaks very much valued this service and described it as a critical support for the care placement. 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. Social workers also indicated a 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.

### **7.6 Family contact**

Most disabled children maintained contact with their birth parents. Where contact was planned and regular, most young people reported it to be a positive experience and something that they looked forward to. Some disabled children and young people expressed their happiness at seeing birth family members during interviews. Others expressed their annoyance regarding the restrictions imposed in relation to frequency and duration of contact with all of these disabled children and young people stating that they wanted more contact, more often. Parents expressed similar views.

Carers, parents and social workers all stressed the importance of sibling contact and contact with extended family members. However, there were also challenges related to contact with birth family requiring support from carers and social workers. Some disabled children appeared, according to their parents and carers, to become unsettled following contact. This especially appeared to be the case when there were strained family relationships.

Overall, contact was actively supported by all where possible. Indeed, non-relative foster carers often went to great lengths to facilitate contact some distance from their homes. Family contact arrangements often required careful planning and sometimes structured supervision and support to ensure it was a positive experience for the disabled child. The nuances of family contact in kinship care placements were also highlighted where boundaries could easily blur.

### **7.7 Perspectives on disability and identity**

Disabled young children did not have a strong sense of identifying themselves as disabled and only a few articulated their identity through the prism of impairment. At times, this resulted in disabled children and young people disassociating from disability or mental health services.

Older disabled young people had a deeper awareness of their impairment experiences and shared their views on how it impacted on their lives. Young people diagnosed in adolescence described a process of still making sense of their impairment and its impact on their sense of self. Social workers also highlighted the importance of early identification of impairment in order to secure the right type of services at the right time and to avoid negative consequences for disabled young people.

Some parents and carers focused on the child or young person's deficits whilst others highlighted their capabilities and positive aspects of their lives. A few foster carers explained their efforts to counter low expectations for the child in their care and to encourage their continued development and progression.

In addition to impairment as an integral part of disabled children's identities, knowledge of life story, connection with birth family, understanding parental impairment and making sense of a care identity were other important aspects of identity. 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.

### **7.8 Perspectives on everyday lives**

Disabled 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 reported positive experiences of schooling, their engagement in social activities and high aspirations for their futures. Social workers also highlighted 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.

Several disabled children and young people highlighted their experience of being treated differently because of their disability. Feelings of being different were particularly evident in different areas of their daily lives in particular in relation to engaging in friendships where sometimes there were limited opportunities and experiences of bullying. Several disabled children and young people spoke of their experiences of being bullied especially at school. 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, including low self-esteem, anxiety and mental ill health.

Experiences of bullying in schools were exacerbated by the school not dealing with the problem. Some children talked about how they tried to draw attention to the problems they were having but to no avail. For some, this resulted in inappropriate

reactive responses from disabled children and young people resulting in their exclusion or withdrawal from school. In addition, bullying at school could exacerbate behavioural issues at home.

Parents and carers also discussed disabled children and young people's experiences of bullying and the need for more effective school strategies to deal with bullying behaviour and support disabled children who have experienced bullying. Social workers were also concerned about bullying that disabled children had experienced both in school and in the community and called for improved school responses to bullying, particularly for those vulnerable to persistent bullying which has a lasting negative impact on their lives.

### **7.9 Being heard and involvement in decision making**

Most of disabled children and young people were aware of their looked after child reviews as a forum in which decisions about their lives were taken, however, few of the younger children attended their LAC review. Other disabled children and young people reported being involved in their review and contributing their views.

Overall, disabled children and young people reported mixed experiences of having their views listened to which could be a source of frustration. Parents and carers also reported mixed experiences of disabled children and young people's involvement in decision making. Some positive views were expressed in relation to the child's engagement, interest and satisfaction in the decision making forums. Others felt that the child's impairment may restrict their opportunities to have a real say in decision making. However, levels of participation were affected by child's impairment but also the attitude, knowledge and skill of the worker.

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 referred to the contribution forms that are used to ascertain the perspectives of disabled children and young people prior to LAC reviews and others highlighted the limitations of these structured processes and used more creative approaches.

However, social workers also highlighted the lack of consideration on how to effectively involve all disabled children in decision making and that 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 and that there is still a reliance on carers to represent their views.

### **7.10 Counselling and advocacy**

Disabled young people identified various people in whom they could confide or go to if they had a problem. They mentioned teachers, social workers, foster carers and birth parents. Most of young people were also able to comment on who they would turn to for different types of issues. However, only two young people had accessed formal counselling services.

None of the disabled children and young people had experienced access to independent advocacy services. However, social workers described other cases where children's advocates, in similar cases, had played important roles in meetings. These advocacy roles were seen as particularly important 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 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.

### **7.11 Social work roles**

Disabled children and young people had contact with a range of social workers including residential social work and fieldwork social work from child, disability and/or mental health services. Given the range of social work involvement, diverse social work roles were described by children, their families and social workers themselves.

Disabled children and young people described their social workers as listening to them, doing home visits to them and taking them on outings. Social workers were also identified as key sources of support at difficult times by disabled children and young people.

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. Some parents gave mainly negative accounts of engagement with social work services, often due to feeling a lack of control over social work decisions to remove their children from the birth family home.

Carers also highlighted support from social workers in terms of understanding their family needs, advocating for access to services, listening and offering advice in a non-judgemental way.

### **7.12 Relationships with social workers**

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. Most children and young people described a positive

relationship with their social worker. The characteristics and qualities they valued included sensitivity, taking time to get to know family members, a non-judgmental approach and working in partnership. A few disabled children and young people had less positive views about the quality of their relationships with social workers. Concerns included: not enough time spent together; unreliability; and staff turnover.

Parents and foster carers also valued qualities such as partnership, respect and being kept informed. Some felt that at times that their opinion was not valued and that they were not kept informed. They also felt that not all social workers were attuned to the wider needs of their family.

Inconsistency in social work support was an issue raised by most respondents as it was difficult to work effectively with social services when there were multiple changes of social worker and some families felt that they were missing out on services as they had no-one who knew their case to advocate for them. Indeed, a few parents were unsure who their child's social worker or keyworker was at the time of interview. In addition, disabled children and young people recalled periods of time when they did not have an allocated social worker due to staff changes.

### **7.13 Social work training needs**

Social workers spoke of the need for access to bespoke training particularly in relation to different types of impairment and communicating with disabled children. It was noted that social workers in children's services teams who were not trained in disability issues and may struggle with their responsibilities for looked after disabled children, particularly if they could access advice or support from children's disability services for these cases.

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

### **7.14 Current challenges facing social work services**

Several challenges were identified by social workers and their managers including: limited resources, inter- and multi-disciplinary working, access to specialist services and unmet need.

Working in a climate of austerity was a consistent theme. Senior managers emphasised the lack of adequate investment in children's disability services, particularly in comparison to other health and social care services in NI compared with funding for disabled children's services in other parts of the UK. Amongst social workers, there was a general view that limited resources ultimately resulted in families not being able to access support when they need it most. Particular pressure

points were noted such as: the early stages post-diagnosis when families are adopting new roles caring for a disabled baby; and transitions from home to school, from childhood into adolescence and from adolescence into adult life.

There was also an awareness that different organisational norms across Trusts could impact on the consistency of service delivery across NI. Disabled children in out-of-home care could be known to several teams due to a previous history of social work involvement or multiple presenting needs. Children known to more than one social work team could have several different allocated social workers for varying periods of time. In some of these cases, however, it was noted that co-working across disability and child care teams provided some consistency for families during child protection processes. Furthermore, families transferring across teams had the opportunity to establish new relationships with new social workers when their existing relationships had been fraught due to child protection investigations and/or court proceedings. However, most managers emphasised the need for clear working relationships between teams especially around the transfer of cases.

Social workers highlighted that they worked with a wide range of professionals in both the statutory and voluntary sectors across health, education and social care services. 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 retreat back to their own disciplinary boundaries.

In relation to accessing specialist disability or mental health services, it was noted that tight eligibility criteria were being used across services resulting in longer waiting lists, reduced access to specialist support and increasing pressure on looked after child teams to be the only service provider for looked after disabled children and young people. However, staff in looked after child 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.

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.

Similarly, varying eligibility criteria for access to specialist services were reported in addition to waiting lists for some services and delays due to lack of diagnosis. Exclusion from children's disability services could restrict access to other sources of support such as short breaks or social opportunities during summer holidays. Direct

payments were suggested as a more recent method for funding services, however, some social workers lacked knowledge about how to set up direct payments and indicated that training was needed.

Furthermore, although there has been policy direction away from only using IQ measures to determine access to disability services, most Trusts still used severity of impairment as part of their eligibility criteria for children's disability services. Some Trusts were moving towards a more needs-based approach, however, the implementation of such an approach is still in development and the need for a regional approach to promote equal opportunity across NI was emphasised.

For children who had accessed child and adolescent mental health services social workers spoke highly of this service. However, there was some frustration with disabled children not actually being able to access the service. Similar themes were noted in relation to LAC therapeutic services.

There were concerns about the transition from children's disability/mental health services to adult disability/mental health services. Delays in assessment and higher thresholds for access to adult services, and a reduction in support services were commonly highlighted. Furthermore, some social workers reported struggling to implement plans for young disabled person transitioning from care due to the lack of availability in preferred supported living placements.

With regards to access to other services some young people talked about their engagement with voluntary sector services. VOYPIC, NIACRO, Positive Futures, Home start, Surestart, Mencap, Barnardo's and Autism NI were all mentioned. 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.

Social workers and team managers were acutely aware of the range of unmet need for disabled children and young people and their families. Major gaps in the availability of short breaks and specialist or therapeutic support for disabled children, the extent of alternative care placements within jurisdiction and community based interventions were all highlighted.

### **7.15 Perspectives on good practice**

Children, parents and carers positively appraised individual social workers. At a wider level, innovative approaches to practice had been or were being developed including: a CAMHS learning disability service with a single point of entry to trans-disciplinary, preventive mental health services; dedicated posts to focus on the needs of children with ASD and their families; early intervention family support

projects to support parenting and prevent full-time admission to care; and initiatives to strengthen multi-disciplinary working and service user and carer involvement.

### **7.16 Summary**

Case studies produced rich data on the views and experiences of disabled children in out-of-home care and their parents/carers. Continued support was important to birth parents who were working towards reunification with their children and to foster carers of disabled children. Social work practice grounded in partnership with children and families was particularly valued.

The importance of prompt diagnosis, early intervention and family support was emphasised to prevent family or placement breakdown. Eligibility criteria for access to disability or mental health services varied across Trust areas, limiting opportunities to access specialist services. In addition, some services did not accept disabled children if they were already known to another service provider which restricted access to multi-disciplinary services.

Multi-disciplinary working facilitates joined up assessments of need and risk and produces more efficient working practices. However, austerity measures and discipline-specific policies were a challenge to such multi-disciplinary practice. Increasing complexity of need and more challenging behaviours were also reported to be challenging the service system, particularly in relation to identifying appropriate specialist foster or residential care.

For many disabled children, social workers struggled to identify a family-based placement with kinship or non-relative carers. There were also challenges related to permanency planning for looked after disabled children and young people with many experiencing multiple placements and some having repeated separations from birth family. Plans for adoption for several looked after disabled children and young people were also unsuccessful.

The views of disabled children highlight ongoing concerns about bullying and inadequate responses to keeping them safe in schools and local communities. In addition to these disabling experiences, children and young people had often experienced abuse or neglect and separation from family. Despite these experiences, few had accessed therapeutic counselling or advocacy services.

There were mixed reports from disabled children regarding the extent to which they were consulted and listened to. Inaccurate assumptions about disabled children's inability to communicate and limited training on alternative communication styles for social workers contributed to the exclusion of disabled children's perspectives in decisions affecting their lives.

## **8.0 DISCUSSION AND RECOMMENDATIONS**

Given the lack of research with disabled children and young people in out-of-home care noted in the review of literature for this project, this study makes a significant contribution to our knowledge of the population of disabled children and young people in out-of-home care and our understanding of their particular needs and care experiences. The study is also unique in that it captures the views of disabled children and young people, and those of their birth parents and carers which provides further insight into their care and family contexts. Finally, the findings from interviews with their social workers and senior managers help to elucidate the challenges for professionals and service providers aiming to meet the needs of disabled, looked after children and young people.

This report has presented a comprehensive picture of the core issues relating to the care and protection of disabled children and young people in NI. There was much evidence of good professional practice, including examples of partnerships with families and integrated working. However, there are also clear priority areas for service development and improvement. These are outlined below under six core themes for service improvement that should be addressed by policy makers and service planners, commissioners and providers to more effectively address the needs of disabled children and young people in out-of-home care. It is important to note that these thematic priorities also have direct 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.

### **8.1 Early intervention and family support**

The profiling phase of the study provided evidence that disabled children and young people continue to be over-represented in the care system. The number of fully looked after disabled children and young people represented 11.2% of the total LAC population in the same period. This figure compares with census data reporting that 7% of the general child population in NI are disabled (NISRA, 2011).

Preventive rather than crisis driven practice is a recurrent theme in the research findings. Early diagnosis and early intervention to both meet family support needs and address safeguarding concerns were repeatedly emphasised by participants in the case studies as key aspects of good practice that may reduce this over-representation. Without a clear diagnosis, children and young people struggle to access to essential support services, parents lack specialist advice how best to meet the needs of their disabled child and essential supports such as short breaks are inaccessible. In this context, families can be under high levels of stress which can lead to parental ill health, family breakdown and/or abuse and neglect.

There is also a clear message from the case studies that access to specialist services should be based on an assessment of need rather than level of impairment; and that variance in the availability of services across Trust areas in NI should be addressed to ensure equity.

**Recommendations:**

1. Earlier diagnosis and prompt multi-disciplinary responses to parental/carer concerns about their child's growth and development are essential.
2. There is a need to increase the availability of short breaks for disabled children and their families to reduce the risk of family breakdown and intervene in a preventive capacity before family crises escalate.
3. Eligibility criteria for access to children's disability services should be based on need rather than a measure of severity of impairment and should be equitable across the region.

## **8.2 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 and clear pathways to services to meet their own physical health and emotional needs, particularly if there is a possibility of reunification with their disabled child.

Disabled children in out-of-home care who have experienced much loss, trauma, abuse or bullying also require further support. Indeed, the high levels of mental health needs amongst the LAC population, often co-existing with other impairments, is further evidence of their need for therapeutic intervention. However, few disabled children in our study were accessing therapeutic or counselling services.

In the case studies, professionals highlighted procedures and protocols for practice whilst disabled children, birth parents and carers emphasised the importance of trust-based relationships and partnerships with social services. Social workers who took time to get to know them and build solid working relationships with the child and their family were more positively appraised in comparison to those who simply followed procedures. Such partnership-based working was also more effective as it created more opportunities to identify need and intervene at an early stage; respected the ongoing parental responsibility of birth parents and facilitated more positive experiences of family contact.

**Recommendations:**

4. Social workers need to invest time into building close working relationships with disabled children, birth parents carers to better understand their needs and facilitate partnership-based approaches to their practice.
5. Specialist training and targeted support is required for non-relative and kinship foster carers caring for disabled children, including short breaks.
6. 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.
7. Therapeutic services for looked after disabled children and young people require development, including counselling, life story work and peer mentoring that addresses complex identity issues for disabled looked after children in out-of-home care.

**8.3 Inequity in service access**

The variance in levels of service provision across Trusts noted in both stages of the study reflect different eligibility criteria for access to childhood disability or mental health services and highlight the inequities in service provision for disabled children and young people across the region. There is much concern about lack of access to CAMHS for those already known to children's disability services. Likewise, although the survey found that the population of disabled children and young people in out-of-home care tend to be older, they had limited access to leaving care and transition services.

There seems to be an over-reliance on one service to meet the heterogeneous needs of a disabled children. Silo working may reflect the context of resource constraints, however, it creates significant barriers to important specialist services, such as, therapeutic programmes for children in care or specialist mental health care. Whilst children's disability services may be best placed to support disabled children and their families, they do not have skills or expertise in LAC therapeutic programmes or specialist mental health care. Similarly, generic child care teams do not have knowledge of disability issues or access to disability-related support services.

**Recommendation:**

8. A regional review of eligibility criteria for access to children's disability and mental health services is urgently needed to ensure equity across the region and to clarify pathways to support for children with needs which require a cross-disciplinary and multi-agency response.

#### **8.4 Investment in placement options and pathways to permanence**

A broader range of placements is required to meet the needs of disabled children and young people entering the care system, and to ensure they have opportunities to enjoy family-based care and permanent care arrangements.

Family-based care settings are important given case study findings that highlighted inadequacies in mainstream residential placements due to issues relating to physical inaccessibility, unpredictable group dynamics and staff with limited disability-related experience or training. Specialist residential care was highly valued but, given the lack of such placements in NI, these were often out of jurisdiction and highly costly.

Increased opportunity for permanence is a key priority given the high level of placement instability for fully looked after disabled children in comparison with the general LAC population, with many having multiple placement moves which had a knock on effect on schooling, family contact and community inclusion.

Whilst all efforts should be made to reunify children with their birth families, there is also some indication that repeated returns home for disabled children were in the context of limited alternative placement options and caused much biographical disruption for disabled children and further instability. Social workers also reported significant challenges in their efforts to secure a long-term placement for disabled children due to a lack of specialist fostering and shared care placements.

Adoption offers one of a number of permanent care pathways, however, disabled children were considered to be one of the hardest groups to place for adoption due to their impairment-related needs or uncertainty about their future health and development.

#### **Recommendations:**

9. A review of the availability of foster and specialist care placements for disabled children is required to scope current provision regionally and inform investment in family-based care for disabled children which may offer routes to permanency and cost efficient specialist residential care within NI for those with higher level and more complex needs.
10. There is a need to explore the potential to develop shared care placements, offering 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.

### **8.5 Integrated, multi-sector working**

All participants repeatedly highlighted the crucial importance of multi-disciplinary and multi-sector working. In order to address the increasing complexity and heterogeneity of disabled children's needs, current systems need to develop more integrated ways of working, including co-located teams.

Disabled children and young people and their families need holistic assessments of need and risk, and a joined up approach to responding to identified needs. Such cross-disciplinary practice can also lead to more creative and efficient ways of working, in the context of resource constraints and service cutbacks.

However, at a structural level, disciplinary specific policies, procedures and investment must be addressed to facilitate a culture of integrated working in practice. In addition, with an emphasis on tiered levels of service provision, there is much potential to further develop partnerships with community and voluntary sectors.

#### **Recommendations:**

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. Investment in services should promote integrated working with a shift from resourcing uni-disciplinary services and training towards budgets targeted at multi-disciplinary, integrated provision and co-located teams.

### **8.6 Promoting disabled children's participation**

A fundamental concern for disabled looked after children and young people is the importance of being listened to and having a say in decisions affecting their lives. There were some very good examples of disabled young people being involved in decision making in relation to their placements and birth family contact. However, in many cases, disabled children felt more excluded.

The importance of ascertaining the voice of disabled children was not always recognised or fully explored 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 the severity of their impairment or a lack of staff confidence in their skills for using alternative communication methods.

In addition, 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. There is a need to develop professionals' understanding of impairment effects and the rights of disabled children and young people.

**Recommendations:**

14. Multi-disciplinary training on disability awareness and alternative communication approaches should be provided for all professionals working with disabled looked after children to increase knowledge of impairment effects and participatory practice that facilitates disabled children's expression of their wishes and feelings. Disabled children and young people and their parents/carers should be involved in such training initiatives.
15. Training is required to raise awareness of the United Nations Conventions on the Rights of Children and People with Disabilities and statutory responsibilities in relation to disability discrimination and human rights law in NI. This is particularly important given the disabling experiences disabled children and young people experience including bullying and social isolation.
16. There is an urgent need to develop advocacy services for disabled children and young people across the region to ensure their rights to independent representation and support are upheld.

## **9.0 CONCLUSION**

Given the paucity of research on disabled children's out-of-home care experiences, this makes a significant contribution to our understanding of the characteristics, needs and experiences of this population. Importantly, our study is also unique in: profiling of the population across NI; using participatory methods to ascertain the views of disabled children living in out-of-home care; and including the perspectives of birth parents and carers of disabled children placed in out-of-home care.

Although there was some evidence of best practice in terms of partnerships with families and integrated working, the invisibility of disabled looked after children in policy documents seems to be replicated in practice with a lack of attention to disabled children as a distinct group requiring targeted attention in our care system. The study demonstrates that these disabled children face a range of complex challenges and inequities that require prioritisation in policy and practice initiatives to raise awareness of their specific and diverse needs.

The profiling survey provides evidence of the ongoing over-representation of disabled children in the care system. Reflecting themes from the literature, there are

more disabled, older boys with intellectual disabilities. The other main impairment category is mental health, often co-existing with other impairments, with those this group of children at higher risk of placement instability and risk-taking behaviours.

The case studies provide important insights into disabled children's care pathways, family contexts and out-of-home care experiences. Before entry to care, prompt diagnosis, early intervention and family support is critical. Disabled children come into care for many of the same range of reasons as their non-disabled peers, however, they are at greater risk of family breakdown due to inadequacies in family support services. Following admission to care, a greater range of placement choice and more ongoing support for parents and carers is needed. Relationships and trust-based partnerships are emphasised as the cornerstone of effective support and stable care placements.

The findings clearly indicate that service created boundaries that promote uni-disciplinary working and prevent access to specialist services must be eradicated. Disabled children in out-of-home care require a cross-disciplinary and multi-agency response to their multiple and complex needs beyond single impairment-focused services. There are also deep underlying injustices for disabled children in our society, including persistent bullying, vulnerability to abuse and social exclusion which are all the more pertinent for disabled children who have been removed from their birth families and local communities. Greater efforts must be made to listen to disabled children and promote their right to receive a high standard of care and protection and enjoy the same opportunities afforded to their non-disabled peers.

At a local and global level, there are major gaps in empirical research on the experiences of this population. Further studies replicating this study's methodological approach would extend our knowledge and allow for comparisons across jurisdictions and cultures. In addition, there are areas for further research, including outcomes-based research and 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.

Overall, this study presents a comprehensive picture of the core issues relating to the care and protection of disabled children and young people to inform policy and practice and contribute to the knowledge base on out-of-home care for disabled children and young people. The recommendations outlined in the previous sections clearly indicate priority areas for service development and improvement. We encourage policy makers, commissioners and service providers to heed the voices of the disabled children presented in this report and to use the findings of this report to inform their future decisions about investment and improvements in services for disabled children and young people and their families.

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