



## ***You Only Leave Once?***

# **Transitions and Outcomes for Care Leavers with Mental Health and/or Intellectual Disabilities**

## **FINAL REPORT**

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## 1.0 INTRODUCTION

Whilst most disabled children and young people live safely with their birth families, disabled children are still at higher risk of abuse or neglect than non-disabled children (Stalker & McArthur, 2012) and are over-represented in the population of young people leaving care in Northern Ireland (NI) (DHSSPSNI, 2015a). However, very few studies have specifically examined the characteristics or experiences of disabled care leavers as they transition from care into their young adult lives. This report summarises the findings of the YOLO study that sought to address this gap in knowledge by investigating transitions and outcomes for care leavers with mental health and/or intellectual<sup>1</sup> disabilities in NI. Care leavers with mental health and/or intellectual disabilities are the main focus as the study is funded under the Bamford<sup>2</sup> programme of research and these are the two dominant impairment categories within the care leaver population, often co-existing.

### 1.1 STUDY AIMS AND OBJECTIVES

The main research question for the study was: How well does the interface between child and adult services meet the support needs of care leavers with mental health and/or intellectual disabilities making the transition into young adult life? The study sought to address gaps in knowledge about the transitional experiences of this population of care leavers within the current health and social care context of separate child and adult services.

The overall aim of this research was twofold: (1) to examine the profile and characteristics of care leavers with mental health and/or intellectual disabilities; and (2) to investigate how best to configure the interface between child and adult service systems to meet transitional needs. The specific objectives of the research were to:

1. Examine the characteristics of care leavers with mental health and/or intellectual disabilities.
2. Examine how the particular support needs of these care leavers are met, or could be met, as they transition from child to adult services.
3. Explore how care leavers with mental health and/or intellectual disabilities perceive their experience of transition and their support needs in young adult life.
4. Identify examples of best practice in the delivery of services for these care leavers.
5. Explore the challenges and opportunities for commissioners, planners and practitioners aiming to develop cohesive services to more efficiently and effectively meet the transition needs of this population.
6. Establish baseline data on this population of care leavers to inform further research examining their adult pathways and longer-term outcomes in adult life.

In order to address these aims and objectives, there were three key stages of the study: (1) a review of policy and research literature on the needs and experiences of disabled care leavers (Kelly et al., 2014a, b); (2) a survey providing anonymous profiling data on the population of disabled care leavers

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<sup>1</sup> Throughout the report, the term 'intellectual disability' rather than 'learning disability' is used as it is a globally recognised term. As service providers in NI use the term 'learning disability' this term will be used in the report when describing 'learning disability services'. On occasion, we use the term 'disabled care leavers' to refer to the full range of impairment types covered in the UNCRPD definition that the study employed.

<sup>2</sup>The Bamford Review focused on reviewing and improving services for people with mental health and/or intellectual disabilities.

in NI on 30 September 2013 (Kelly et al., 2016a); and (3) case studies of a sample of this population involving reading case files and interviews with young people, carers, birth parents and social workers (Kelly et al., 2016b).

The present final report provides a summary of the aims, methods and key findings of the study. However, we encourage readers to refer to the full reports on each stage of the study for further details (Kelly et al., 2016a & 2016b). Each report is available on the following web link: <http://www.research.hscni.net/bamford-implementation-commissioned-call-portfolio>.

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

The report begins with an overview of the service and policy context for the study and the findings of the literature review (Kelly et al., 2014a, b). This is followed by an outline of the methodological approach, including the study's inclusion criteria, survey method and peer research approach.

An overview of the profile of care leavers with mental health and/or intellectual disabilities in NI is then presented including: demographic characteristics; impairment types; family contact; living arrangements; engagement in education, training or employment; safeguarding and risk; and access to support services.

A summary of the findings of the qualitative case study phase of the research is then reported, drawing on the views and experiences of care leavers with mental health and/or intellectual disabilities; and the perspectives of their parents/carers and social workers. The report concludes with recommendations for future research, policy and practice.

## **1.2 BACKGROUND TO THE STUDY**

In designing and conducting the study, it was important to take into consideration the complex service context for care leavers with mental health and/or intellectual disabilities in NI and the existing information available on this population from data routinely collected in Departmental statistical returns for care leavers in NI.

### **1.2.1 The Service Context**

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): Western, Northern, Southern, South-Eastern and Belfast. The geographical spread differs considerably across Trusts, with a mix of urban and rural locations.

Under the Children (Leaving Care) Act (NI) (2002) and amended Children (NI) Order 1995 a care leaver is defined as a person who has been looked after (in out-of-home care) for at least 13 weeks, since the age of 14, and who is in care on their 16<sup>th</sup> birthday. The status of care leavers can be further subdivided into eligible, relevant, former relevant and qualifying young people.

- An eligible young person is aged 16 or 17, has been looked after at least 13 weeks since the age of 14 and is currently looked after.
- A relevant young person must be aged 16 or 17, be eligible and have left care.

- Former relevant young people are aged 18-21 (or older if they are in further or higher education or training) and, before turning 18, were either eligible and/or relevant young people.
- Qualifying young people are aged under 21 (under 24 if in education or training) who ceased to be looked after in a variety of other settings, or privately fostered after the age of 16).

As young people leave care, social service support is usually transferred from Looked After Children's (LAC) teams to 16+ (or aftercare) teams who lead on the fulfilment of statutory responsibilities for care leavers.

Care leavers who meet the criteria for Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) may also transfer across these services, however, 16+ teams continue to lead on these cases.

Care leavers with intellectual disabilities who meet the criteria for child and adult disability services may also experience a transfer across these services. In some Trusts, 16+ teams continue to lead on these cases until the young person transitions to adult services when the case may be co-worked for a short period of time. However, in two Trusts, children's disability teams lead on all cases relating to disabled children in care or disabled care leavers until they transition to adult disability services.

It is also important to note that in NI, children's services are based on an assessment of need for social care support rather than level/type of impairment whilst adult disability services are based on impairment type (e.g. Community Learning Disability teams) and level of impairment, with those meeting the eligibility criteria usually assessed as having at least a moderate to severe level of impairment. Likewise, AMHS are provided to adults who have symptoms of a severe and enduring mental illness.

As a result, disabled care leavers may experience multiple service transitions as they leave care and may have their level of impairment re-assessed to determine eligibility for adult disability or mental health services. Of course, some disabled care leavers do not meet the criteria for child or adult disability/mental health services (for example, those not yet diagnosed or with borderline to moderate levels of impairment) and will only have access to services from 16+ teams.

When 16+ teams are not leading on cases, timely and robust transition planning should be undertaken to ensure young people being case managed by child or adult services continue to access any leaving care entitlements (e.g. assistance with education, training or accommodation).

Responsibility for disabled care leavers with multiple impairments is less clear and may depend on the main impairment type. The type of team holding a disabled care leaver's case is important because it impacts on young people's access to a full range of services. For example, staff in 16+ teams will not have direct access to specialist disability or mental health services. Similarly, staff in disability or mental health teams may not have expert knowledge of issues relevant to leaving care or possible sources of support available for care leavers.

### **1.2.2 The Care Leaver Population in NI**

There are two sources of statistical information on the care leaver population in NI relevant to the time period of the study. The first is the Departmental statistical bulletin on care leavers in NI for 2013-14 (DHSSPSNI, 2015a). This report is based on OC1 (care leavers aged 16-18) and OC3 (care leavers aged 19 who had been in care for the previous three years) data returns from Health and Social Care



Trusts (HSCTs) to the Department, designed to monitor and assess outcomes for care leavers. Whilst this report provides a useful overview of the population of care leavers aged 16-19 years, it excludes care leavers in other age groups and those who had been in care for shorter periods. The second source of data on care leavers is the HSCB's Delegated Statutory Function (DSF) data return which is collected bi-annually. This data return includes the whole population of care leavers on a given date, including those aged 21 and over. The DSF return on the care leaver population at 30 September 2013 (HSBC, 2013) is the most relevant to the current study as the same data collection point (at 30 September 2013) was adopted for the current study to facilitate identification of young people meeting the study criteria and to allow for comparisons with the overall care leaver population.

The DSF return for that period reported a total of 1339 care leavers in NI, with 49% male and 51% female. The majority were aged 16-17 years (38%), closely followed by those aged 18-19 years (36%). There was a sharp decline in numbers of care leavers in the older age ranges with 18% aged 20 years and only 9% aged 21+ years. Overall, 11% of the care leaver population were parents and almost half of these were lone parents. In addition, 8% of the care leaver population had criminal convictions within the previous year.

The majority of care leavers were reported to be in the 'former relevant' category (60%), followed by those in the 'eligible' category (35%), with small numbers on the 'relevant' and 'qualifying' categories. Most 'eligible' care leavers were under a Care Order (59%) with a further 38% being voluntarily accommodated. The highest number of care leavers was in the BHSCT (28%) and the lowest was in the SHSCT (14%). Overall, 17% of care leavers did not have access to a Personal Adviser (PA), 7% did not have a pathway plan and 3% did not have a completed needs assessment.

Most 'eligible' care leavers were in foster placement settings (34% non-relative; 21% kinship), followed by children's residential homes (17%) and being placed at home (12%). The two main accommodation settings for other care leavers were in a tenancy arrangement (34%) or with a former foster carer (GEM<sup>3</sup>) (27%) followed by living at home (16%) or with relatives/friends (9%).

Within the population of 'eligible' care leavers, 94% were engaged in education, training or employment, with 4% disengaged and 2% in the 'other' category (sick, disabled, parent/carer). These figures change for other categories of care leavers with 71% engaged in education, training or employment, with 22% disengaged and 7% in the 'other' category (sick, disabled, parent/carer).

Within the care leaver population, 13% were disabled, with the two main impairment types being Autistic Spectrum Disorder (ASD) (43.6%) and intellectual disability (41.9%) (similarly, the Departmental statistics reported 12% of the cohort were disabled) (DHSSPSNI, 2015). By comparison, just over 6% of the young people aged 16-18 years in NI have a long-term limiting health condition/disability (DHSSPSNI, 2015:12) and only 5% of those receiving Disability Living Allowance in May 2014 were aged 16-24 years (DSD, 2014). These figures on disabled care leavers, therefore, reveal the over-representation of disabled young people in the care leaver population in NI.

The DSF report also found that 17% of the population of care leavers at 30 September 2013 had mental health needs requiring service intervention and 9% were receiving treatment for self-harm. It is not clear in the DSF report whether there is overlap between these two groups and it is also not known whether or not some of these care leavers with mental health needs also had co-existing disabilities.

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<sup>3</sup> The 'Going the Extra Mile' (GEM) Scheme promotes post-care continuity and stability by supporting foster carers to continue to provide care, support and accommodation for young people aged 18 – 21 whom they have previously fostered

### **1.3 POLICY CONTEXT**

There are four key policy areas relevant to care leavers with mental health and/or intellectual disabilities: child care, mental health, learning disability and transition (Kelly et al., 2014a). These four domains of policy must also be considered in the context of broader international and Northern Irish rights-based, strategic policies.

#### **1.3.1 The Rights-Based Policy Context**

At a global level the *United Nations Conventions on the Rights of the Child (UNCRC) (1989)*; and the *Rights of Persons with Disabilities (UNCRPD) (2006)* lead the way in promoting equality, human rights, access to services and social inclusion for disabled children and adults. Some of the Articles within the UNCRPD focus on areas applicable to care leavers. For example, disabled people's right to access education and training (Article 24), an adequate standard of living and social protection (Article 28) and equal opportunities for employment (Article 24). Despite the enshrinement of rights for disabled people in these international conventions, recent reports from the World Health Organisation (2010, 2010a) and UNICEF (2009) highlight persistent barriers and issues that still need to be addressed regarding disabled children and young people in care. A common thread throughout the international policy documents is the need for a universal approach to improving the lives of disabled children and young people through service collaboration and clear targeting of the specific needs of this population. In addition, in 2010, the UN General Assembly issued *Guidelines for the Alternative Care of Children* which set out key responsibilities of State Parties to provide appropriate aftercare and follow up support to ensure young people are prepared as early as possible for leaving care and have opportunities to develop life skills and access financial support to enable them to progress to independent living and enjoy community integration.

Reflecting the principles of the UNCRC and UNCRPD, five key statutes in NI address the rights of disabled people (including disabled children and young people). The *Human Rights Act (1998)* and the *Northern Ireland Act (1998)* aim to safeguard the rights of all people in NI and ensure that statutory bodies promote equality of opportunity between disabled and non-disabled people. The *Disability Discrimination Act (1995)* and *Disability Discrimination (NI) Order (2006)* focus specifically on disability rights, expanding on the definition of disability to include those with mental health needs and seeking to address discrimination on the grounds of disability and promote equal access to services. The requirement for service user involvement under the *Health and Social Care (Reform) Act NI (2009)* highlights the rights of service users (including all care leavers) to be actively involved in decisions about services they use and future policy and practice developments. These rights-based policies set the scene for child care, mental health and learning disability policies relating to care leavers with learning disabilities and/or mental health needs.

#### **1.3.2 Strategic Policy Drivers**

The Transforming Your Care Review (DHSSPSNI, 2011), Ten Year Children's Strategy (OFMDFM, 2006) and Disability Strategy (OFMDFM, 2013) are three key strategic drivers for policy affecting the lives of care leavers with mental health needs and/or learning disabilities in NI. The outcomes statements in the *Ten Year Children's Strategy (OFMDFM, 2006)* have been used as a guiding framework for children's policy in NI, including the recently published standards for leaving care services (DHSSPSNI, 2012). Overall, the strategy adopts a whole-child perspective that promotes the development of high

quality universal services alongside targeted interventions for particular groups, including separate attention given to care leavers, young people with mental health needs and disabled young people in transition.

The impact of the *Transforming Your Care* (DHSSPSNI, 2011) review is evident in policy documents introduced since the review, including the commissioning plans for health and social care services during the study timeframe (HSCB & PHA, 2012:92). The review set out a future model for integrated health and social care grounded in a commitment to personalised and preventive services, integrated and localised planning, and high quality health and social care. The need for better service provision for people with mental health needs and/or intellectual disabilities and the growing number of looked after young people in NI are acknowledged. However, the review does not specifically address the difficulties faced by these young people as they leave care or the additional support they may require as they transition from child to adult services (DHSSPSNI, 2011).

The *Disability Strategy (OFMDFM, 2013)* is grounded in a rights perspective although its impact remains to be seen. One of its strategic priorities is improving young disabled people's transitions from child to adult services. Other relevant priorities include disabled people's rights to an adequate standard of living, employment, lifelong learning and skills training. However, the strategy does not consider these issues specifically in relation to disabled young people leaving care. A timeframe or concrete targets for the implementation of the priorities are also not provided, although Government commitment to each area is emphasised in order to address the rights of disabled people in NI.

These three strategic documents provide the direction of travel for the development of child, disability and mental health policy and are in line with the general thrust of the Health Minister's recent statement on a ten year vision for health and social care (DoH NI, 2016) and the Executive Programme for Government (NI Executive, 2016). Across the three strategic documents, young people with a disability, mental health needs and care leavers are addressed but as separate groups. There is little consideration of the combined experience of leaving care with a disability and/or mental health needs. Without that recognition this population, with its combined set of needs, is very vulnerable to being overlooked in future service developments.

### **1.3.3 Child, Youth and Leaving Care Policy**

The main statute governing the care and protection of children and young people in NI is the *Children (NI) Order 1995*, providing a duty to support children in need and their families and to provide substitute care for children or young people where their parent/guardian is unable to provide them with suitable accommodation or care. The Order also emphasises the importance of ascertaining the views and wishes of children and young people, including those with disabilities (DHSSPSNI, 1996).

The *Children's Homes Regulations (NI) 2005* govern the conduct and management of all children's homes with a primary emphasis on the promotion of each child's welfare, which ranges from their basic right for food and clothing to promoting and protecting their health and wellbeing. The regulations account for the additional needs of disabled children and young people and procedures are in place for maintaining records of care leavers, however, supporting the additional mental health needs of children and young people whilst they are living in children's homes or upon leaving is not directly addressed within the regulations.

The *Children (Leaving Care) Act (NI) (2002)* amends the Children (NI) Order 1995 to clearly define care leavers' legal status and to place duties on HSCTs to prevent premature discharges from care, to

improve preparation, assessment, planning and consistency of support for young people leaving care, and to strengthen arrangements for financial assistance. The Act states that the HSCTs should also maintain contact with the child, including but not limited to 'taking reasonable steps to keep in touch' to ensure that the welfare of the child is promoted even after they leave care (DHSSPSNI, 2002: 3). That duty extends until the young person is 21 years or 24 if the Trust is supporting further education and training. HSCTs should also appoint a Personal Adviser (PA) and develop a pathway plan which establishes a programme of further education or training to promote independence and is subject to regular review. Finally, the Act acknowledges that the Trust is expected to assist and support, as well as contribute financially, where necessary to the ongoing education and training of care leavers, including expenses attributed to receiving education and accommodation until the age of 24.

The Children (Leaving Care) Act (NI) 2002 and associated regulations are inclusive of all young people, and, although comprehensive in its guidelines, it does not highlight the specific additional support which may be required by care leavers with disabilities or mental health needs (DHSSPSNI, 2005). The *Children (Leaving Care) Regulations (NI) 2005* provide more detailed guidance for HSCTs on how best to assess and meet the needs of young people preparing to leave care and those who have already left. The regulations include: the qualifying criteria for leaving and aftercare arrangements; the assessment of need preparation and review of pathway plans; the functions of PAs to ensure better support after care; and finally the assistance available for care leavers with regards to education, training, financial support and accommodation. It is noteworthy that the regulations state that accommodation for care leavers, where reasonably practical, should be suitable for those with any form of disability, including a learning disability.

The *Standards for Leaving Care Services in NI* (DHSSPSNI, 2012) highlight the need for person-centred care planning focused on supporting care leavers to: maintain high levels of wellbeing; access suitable housing; achieve their academic potential; and enjoy social inclusion. Two of the eight standards specifically mention planning for additional health or disability-related needs. It is positive to see this consideration of disabled care leavers. However, given the extent of barriers that exist for this population, it would be helpful if their needs were integrated across all standards.

Whilst there does not tend to be a specific focus on disabilities within care leaving policy there are two notable exceptions: *Volume Eight of the Guidance and Regulations for the Children (NI) Order 1995* which has a separate section on the additional needs of disabled young people leaving care; and the Western Health and Social Care Trust's *Good Practice Guidance on Transition Planning for Young People Leaving Care with a Disability* (WHST, 2010). The latter practice guidance document focuses specifically on pathways to support for disabled young people leaving care and transitioning from child to adult disability services (WHST, 2010). Whilst it could be a useful practice guide for the region, it is only a Trust advisory document. *Volume Eight of the Guidance and Regulations for the amended Children (NI) Order 1995* on leaving and after care services (DHSSPSNI, 2005), however, does apply across the region and has legal status. It has a dedicated section on the additional needs of disabled young people leaving care. This guidance highlights the importance of: ensuring suitable training, employment or meaningful day opportunities; addressing sexual health education needs; building self-esteem; increasing ability to make choices, take risks and assume adult responsibilities; and working closely with other authorities such as education or housing to ensure a smooth transition to adult life. It is also noted that particular attention should be given to disabled young people who do not meet the criteria to access adult health and social care services.

Since the end of data collection for the study, there has been a key addition to the child care policy landscape in NI with the introduction of the *Children's Services Co-operation Act (Northern Ireland) 2015*. This Act places a duty on children's authorities to co-operate in the provision of children's

services, including care leavers and disabled young people. As this policy is relatively new, the effectiveness of its implementation is yet to be seen. However, it has potential to facilitate improved cross-sector working in children's services and, therefore, has particular relevance to care leavers with mental health and/or intellectual disabilities who are likely to require a range of services across sectors.

#### **1.3.4 Mental Health and Learning Disability Policy**

Care leavers with mental health and/or intellectual disabilities are also under the remit of disability and mental health policy. The *Health and Personal Social Services (NI) Order (1972)* [amended by the Health and Personal Social Services (NI) Order (1991), the Health and Personal Social Services (NI) Order (1994) and the Health and Social Care (Reform) Act (NI) (2009)] imposes a number of duties including: arrangements necessary to prevent illness and care for a person suffering from illness (Article 7); provision of advice, guidance and assistance (Article 15); and provision of personal medical services (Article 56). Although dating back several decades, Sections 1 and 2 of the *Chronically Sick and Disabled Persons (NI) Act (1978)* also outline the duty to share information and make arrangements for the provision of social services to meet the needs of people defined as chronically sick or disabled, including those defined as having a mental disorder under the Mental Health (NI) Order 1986.

At the time of the study, the main mental health statute in NI was the *Mental Health NI Order (1986)* which addresses the assessment, treatment and rights of people with mental health needs. The Order was applicable to all people in NI and included reference to the role of Trusts when a young person is in care (Article 33), however, the specific needs of care leavers or disabled children and young people were not specifically addressed within the Order. During the study, the new mental health and capacity legislation was in development and this legislation was recently passed by the Assembly as the *Mental Capacity Act (NI) 2016* which combines mental capacity law and mental health law into a single framework (although may not be fully implemented until 2021). The legislation applies to those aged 16 and over, however, there has been much debate over the age threshold, given that children reach maturity at different stages and may or may not have the same capacity to make decisions as an adult (Children's Law Centre, 2009; Black, 2012). The need for advocacy for young people is also emphasised by critics of the age limit in the new legislation to ensure their right to have their views and wishes considered by those deciding on proposed treatment or intervention (Children's Law Centre, 2009).

The *Service Framework for Mental Health and Wellbeing* (DHSSPSNI, 2011a) sets out a total of 58 standards aimed at improving the overall mental health and wellbeing of the population, as well as reducing inequalities and improving the quality of health and social care for people with mental health needs in NI. The standards cover the prevention, assessment, diagnosis, treatment, care and rehabilitation of both individuals and communities who currently have, or are at risk of developing a mental illness. Standard 31 is specifically aimed at children and young people who are transitioning from child to adult services. It highlights the importance of appropriate assessment of needs and the identification of services within adult services for those with mental health needs, in partnership with families and carers. Standard 56 addresses those with learning disabilities and mental health needs. It highlights that people with learning disabilities are four times more likely to experience mental health issues and that access to information and services requires improvement. This standard also outlines a multi-disciplinary approach to meeting the needs of those with dual diagnosis (learning disability and mental illness). Although these standards address the transition from child to adult services and acknowledge the needs of people with mental health and learning disabilities, they do not focus on

the particular experiences of care leavers who have mental health needs and/or learning disabilities (DHSSPSNI, 2011a).

The *Service Model for CAMHS in NI* (DHSSPSNI, 2012b) provides a framework for the integration of health and social care services that emphasises prevention, early intervention and proactive recovery. A stepped care model is proposed to ensure services are matched to service user need and a whole systems approach that effectively links primary care, child health, social care services and specialist CAMHS.

More recently, the *Regional Mental Health Care Pathway* (HSCB, 2014) outlines pathways for access to mental health care and standards of care that can be expected. This document emphasises service user and carer involvement in decisions about their care, person-centred practice and recovery. There is also a focus on building the capacity of individuals to manage their own mental health and wellbeing based on personal safety and wellbeing. Following the service frameworks for AMHS and CAMHS, a stepped care approach is outlined to match individual needs with the right level of support, with intensive/specialist services only being accessed, as required. The care pathway specifies that waiting times for non-urgent appointments following referral should be no longer than 9 weeks, a choice of appointment times should be offered to reflect the individual's personal needs and social circumstances; and non-attendance may be followed up by home visits if the person's wellbeing is compromised. Discharge from mental health care for non-attendance should be a last resort and only following an assessment of the implications for the person's safety and wellbeing.

*The Learning Disability Service Framework* (DHSSPSNI, 2015) provides a total of 34 standards for learning disability services; a number of which relate to young people with learning disabilities and also those who are looked after. The importance of child-centred and co-ordinated services for children and young people is emphasised, as well as the need for multi-disciplinary communication and transition planning for those leaving school or moving from hospital to community-based care. Standard 13 focuses on looked after young people and acknowledges that any child or young person who is unable to live at home permanently should have their placement needs addressed in a way that takes full account of their learning disability. The Learning Disability Framework identifies young people who are looked after and those leaving school as two groups in need of support, however, the combined experience of young people with a learning disability who are leaving school and also leaving state care is not fully addressed.

Over the past decade, *the Bamford Review* has been a leading driver of learning disability and mental health policy in NI, culminating in Departmental action plans outlining the Government's commitment to improving the overall health and wellbeing of those with mental health needs or learning disabilities. However, the action plan for the period 2012-2015 (DHSSPSNI, 2012c) noted key areas for further service improvement including early intervention to promote positive health and wellbeing, more personalised care, stepped care approaches and working more collaboratively to facilitate social inclusion and participation. The plan also outlines the Health and Social Care Board's statutory duty to establish and lead the *Children and Young People's Strategic Partnership (CYPSP)* aimed at improved outcomes for three groups of children: those with emotional and behavioural difficulties; those with disabilities; and disabled young people transitioning from child to adult life. However, no specific reference is made to the additional needs of care leavers with mental health needs and/or learning disabilities who are overlooked within the plan. The report only specifically refers to education transitions for young people with learning disabilities and transitions between CAMHS and AMHS. The continued absence of disabled care leavers moving from child to adult services in the Department's action plans suggests that this vulnerable group is still not being recognised as a priority within disability and mental health policy and service planning.

Since the Bamford Review, further disability-related legislation and policy has been introduced. The *Autism Act (NI) (2011)* aims to ensure that people with autism have access to the same entitlements and opportunities as those with other types of disability. It introduces an amendment to the Disability Discrimination Act (1995) and extends the definition of disability to include impairments affecting participation in normal social interaction or the formation of social relationships. This amendment clarifies the legal definition of disability and ensures that people with social and/or communicative disabilities are afforded the same protection against discrimination. The Autism Act also requires Government Departments to work together to achieve a more coordinated approach to service provision for people with autism and their carers. The subsequent Autism Strategy and Action Plan (DHSSPSNI, 2012a) calls for a planned, co-ordinated approach to services for people with autism and highlights the importance of awareness raising, accessibility, independence, employment; and active citizenship to improve the lives of those with autism. Although it does not specifically refer to care leavers, the strategy does highlight the needs of autistic young people and their families as they transition from child to adult services.

In Northern Ireland there are a range of statutes, policies, and guidance which provide a framework for safeguarding adults. However, there is no single unifying adult protection bill (Montgomery et al., 2016). The *Safeguarding Vulnerable Adults* procedural guidance (DHSSPSNI, 2006), has been replaced by the *Adult Safeguarding: Prevention to Protection in Partnership Policy* (DHSSPS, 2015b). Perhaps the most significant change in these policies is that the term 'vulnerable adult' has been replaced by 'adult at risk' to shift the emphasis and, by implication, responsibility away from the adult onto those who pose a risk to the adult. The policy is underpinned by a commitment to rights-based, person-centred, and collaborative practice. It promotes the prevention of abuse and the building of capacity and resilience within individuals and communities. The focus of adult protection is generic regardless of age or type of impairment, thus, adults with mental health and/or intellectual disabilities are included in this guidance. However, the policy does not specifically address young adults who are leaving state care and who may be particularly vulnerable.

### **1.3.5 Transition Policy**

Transitions for young people with learning disabilities and/or mental health needs are highlighted in a range of law, policy and planning documents. However, much of the emphasis is on transitions from school rather than from public care (DENI, 2005; 2006). For example, under the Disabled Persons (NI) Act 1989 and the Special Educational Needs and Disability (NI) Order 2005, disabled young people in transition from school have a right to an assessment of need and an appropriate transition plan. Under the Carers and Direct Payments Act NI (2002) young disabled people may also use direct payments when they plan to leave home or move into further education, however, Lundy and Byrne (2012) highlighted that the uptake of direct payments amongst young people with learning disabilities and their carers is low in NI.

Whilst there are provisions in place for the general population of disabled young people leaving school, there is much less attention paid to the needs of disabled young people leaving care. For example, although the NIHE (2005) Strategy includes care leavers and those with learning disabilities and mental health problems, it fails to acknowledge the additional needs of individuals who fall into more than one category. It is significant that care leavers with learning disabilities and/or mental health needs still seem to be an invisible group in plans for the future development of transition services. This is surprising as these young people are a group who are vulnerable to poorer outcomes in adult life and are likely to require additional support during the transition to adult life and in their

early adult lives (Mullan & Fitzsimmons, 2006; Rabiee et al, 2001). In particular, the emphasis in current policy on whole child, person-centred and co-ordinated services at the point of transition is particularly relevant to this group who may well need access to child and adult disability, mental health and/or 16+ services, alongside ongoing support with housing, education, training or employment.

## **SUMMARY**

The policy review highlighted a commitment to promoting the rights of disabled children and young people in NI, whilst improving the standard and provision of care they receive. The following six core themes can be identified across the spectrum of disability, mental health, child care and rights-based policies:

- Person-centred approaches focused on individual strengths and aspirations rather than medical models of impairment;
- Inter-agency collaboration and inter-departmental working;
- Access to local, community based services with a focus on social inclusion;
- Systemic approaches based on a 'whole child' approach;
- Stepped models of care incorporating preventive, universal supports, combined, when necessary, with specialist provision; and
- Participation of service users in decisions affecting their lives.

Interestingly, the review identified a short-term approach of publishing a range of strategies, action plans and policy initiatives affecting children's services rather than a much needed longer-term policy focus on the needs of children. The review also raised questions about the impact of various forms and levels of policy on service delivery and development. For example, are commissioners and service providers guided by legislative duties first and foremost or do strategic drivers such as Transforming Your Care or the Learning Disability Service Framework have a dominant influence over decisions about service development? Such questions also have implications for monitoring the impact of policy. Whilst the range of strategies and service frameworks across departmental areas highlight similar themes, such as continuity of care and service collaboration, they often neglect to specify just how these should be implemented and what guidelines or duties are in place to ensure they are effective.

The review also highlighted the invisibility of care leavers in many relevant disability and mental health policies. Coincidentally, disability and mental health issues were often not well-addressed within child care or leaving care policies, although there were a few notable exceptions. It could be assumed that policies addressing the universal needs of all young people/care leavers or disabled young people include care leavers with mental health and/or intellectual disabilities without their specific mention. However, it is more likely that the lack of attention to this particular group across policy domains reflects their position as an overlooked group. This population should be explicitly identified across policy areas to ensure they have a more comprehensive and consistent experience of support as they transition across child and adult service boundaries in NI.



## **1.4 LITERATURE REVIEW**

In the first year of the study, the research team undertook a review of literature on disabled care leavers to identify key findings from previous research and to inform the design of the research instruments (Kelly et al., 2014b). The literature search identified 11 publications based on empirical studies focused specifically on disabled care leavers which were mainly qualitative and conducted in England, Australia, the United States and Canada; and 31 empirical studies on care leavers with mental health needs which were predominantly quantitative and conducted in the United States.

The findings from the review of literature are summarised below in two main sections concerning disabled care leavers and care leavers with mental health needs. This section then concludes with a summary of the overall findings from empirical work in both these areas and the gaps in knowledge about the characteristics, needs and experiences of care leavers with mental health and/or intellectual disabilities.

### **1.4.1 Literature Search**

Literature was excluded from the review if it was focused on general transitions for disabled young people leaving school (unless specifically referring to care leavers) or focused on children and young people in care unless it clearly included those at care leaving age and disaggregated the findings for this older population. Care leaver studies that did not specifically include care leavers with mental health and/or disabilities were also excluded. Some of these studies may have captured data on these young people but did not record mental health/disability and did not differentiate outcomes for this sub-group of care leavers.

Literature included in the review met the following inclusion criteria:

1. Care leaver literature that referred to disability and/or mental health needs;
2. Published between 2000 and time of review (2014);
3. Published in English only;
4. Only full-text journal papers published in peer-reviewed journals; and
5. Grey literature e.g. local publications from voluntary organisations.

A range of electronic databases were searched using keywords relevant to the aims and objectives of the study in the areas of leaving care, mental health and disability. As different terms are used to describe this population globally, international authors in the field were consulted about relevant search terms for literature beyond the UK (for example, ageing out of care or former foster care provided better search hits for US studies). In addition to electronic searches, researchers consulted literature cited by other authors and directly contacted experts in the field of leaving care to identify any further grey literature or unpublished work.

Following searches and screening of results, a total 42 papers were included in the review. Further details of search terms, databases and results of screening of abstracts and full-text documents are available in the full report (Kelly et al, 2014b).

### **1.4.2 Disabled Care Leavers**

The review of literature identified a lack of empirical research on disabled care leavers' experiences. Varying definitions of disability and difficulties relating to identification and access to disabled young

people were some of the reasons provided for this lack of attention (Baker, 2007; Mendes et al., 2013; Harris, 2005). Furthermore, many young people do not identify themselves as disabled even when labelled as such by service providers (Rabiee et al., 2001). Despite these challenges, research in this area has begun to uncover a number of important issues in the drive to better understand the characteristics and needs of this population. For example, disabled care leavers are more likely to leave care at an older age than their non-disabled peers (Rabiee et al., 2001) and experience poor outcomes when they do leave care (Mendes et al., 2013) including contact with the criminal justice system, risk of homelessness and experience of abuse and exploitation after leaving care (Edwards, 2010; Fudge Schormans & Rooke, 2008; Goldblatt et al., 2010; MacDonald, 2010). Furthermore, the outcomes for those young people who fall through the service net in terms of borderline and undiagnosed impairments are even more likely to be poor (Ellem et al., 2012; MacDonald, 2010; Mendes & Snow, 2014).

A major problem for disabled care leavers is inadequate transition planning and aftercare support (Goldblatt et al., 2010; Mendes & Snow, 2014; Rabiee et al., 2001). Lack of resources and timely planning and intervention detrimentally impacts on the support available for preparing disabled young people to transition from care (Fudge Schormans & Rooke, 2008; Mendes et al., 2013; Rabiee et al., 2001). Subsequently, transitions from child to adult disability services can be delayed or experienced as a sudden change in their lives. These disruptions are often compounded by lack of inter-agency collaboration across complex service systems and reduced levels of support in adult services compared to those available from children's services (Mendes et al., 2013; NFCA, 2000).

There is also a shortage of appropriate supported living options for disabled care leavers and concern that some young people move to inappropriate adult placements (such as, facilities for elder care) or unsupported independent living arrangements, return home to unsafe environments or risk homelessness (Fudge Schormans & Rooke, 2008; McConkey et al., 2004; Mendes et al., 2013; Mendes & Snow, 2014; NSW Ombudsman Review, 2004). Given these poor accommodation outcomes, the importance of developing adult advocacy and protection services was noted by several authors (Mendes et al., 2013; National Foster Care Association, 2000; Fudge Schormans & Rooke, 2008; Rabiee et al., 2001).

In addition, the review found that many disabled care leavers are encouraged to enrol for college courses with a narrow focus on independent living skills and low expectations for future employment (National Foster Care Association, 2000; Fudge Schormans & Rooke, 2008; Rabiee et al., 2001). While education and employment are important outcomes for young people, care leavers highlighted additional priorities including: family involvement; friendship; sexuality; parenting; and health (Goldblatt et al., 2010; Rabiee et al., 2001). The value of a network of supportive peers and opportunities for social inclusion was also emphasised by disabled care leavers in Rabiee et al.'s (2001) study as being particularly important in the transition to adult life. These findings highlight the importance of listening to the views of disabled care leavers as their perspectives and priorities can differ significantly from those of carers and professionals. Authors emphasise that disabled care leavers should be placed at the centre of all decisions relating to their transition to adult life to facilitate meaningful, self-determined life choices (NFCA, 2000; Rabiee et al., 2001).

Several studies underline the importance of acknowledging the heterogeneity of the population of disabled care leavers in terms of support needs, community and family context and cultural background. The differing experiences of disabled care leavers were particularly evident in Australian studies by Mendes et al. (2013) and Goldblatt et al. (2010). These studies found that those in rural areas were at an added disadvantage and Aboriginal disabled young people had higher rates of drop-in-support and lower rates of group home support. Disabled care leavers who are homeless and care

leavers who do not meet diagnostic criteria or do not self-identify as being disabled have also been highlighted as over-looked groups in research and practice (Fudge Schormans & Rooke, 2008; Goldblatt et al., 2010; Mendes et al., 2013).

On a more positive note, there is evidence that good practice in planning for transition does produce better outcomes for disabled care leavers. Inter-agency approaches with greater collaboration between child and adult services and early, flexible transition planning helps to ensure transitions are appropriately paced and facilitates access to specialist assessment of health and social care needs (Goldblatt et al., 2010; Mendes et al., 2013). It is also recommended that leaving care plans should document the responsibilities of all relevant agencies and be regularly reviewed at least until the age of 21 to reflect the changing needs of care leavers (Mendes et al., 2013; Rabiee et al., 2001).

### **1.4.3 Care Leavers with Mental Health Needs**

There is clear evidence that care leavers often lack the emotional, social and financial support that families usually provide for most young people their age and are more likely to experience poor mental health than their peers, particularly if they leave care at an early age (16-17 years) (Cashmore & Paxman, 2007; Courtney et al., 2012; Dixon et al., 2006; Teggart & Menary, 2005). The research suggests that mental health problems can precede entry into care, often being related to experiences of abuse and neglect (Dixon et al., 2006; Goldstein et al., 2013; McMillen et al., 2005; Salazar et al., 2011). Less clear is the extent to which this disadvantage ensues during in-care experiences. What the research does suggest is that being in care does not adequately counteract earlier hardship. The strength of this disadvantage increases if the young person's birth parents have a history of psychiatric and/or socioeconomic disadvantage (Vinnerljung et al., 2006). The available literature also indicates differences in type of placement and risk of experiencing mental health problems, with lower rates of mental health needs being associated with kinship type care and higher rates being reported for those in long-term or residential care (Mullan et al., 2007; Vinnerljung et al., 2006).

Existing research clearly demonstrates that the mental health of care leavers can deteriorate on leaving care (Cashmore & Paxman 2007; Courtney & Dworsky, 2006; Dixon et al., 2006; Viner & Taylor, 2005; Vinnerljung et al., 2006). Care leavers face many obstacles as they move out of care including unsuitable and unstable accommodation alongside lack of access to further education (Fowler et al., 2011). Heightened risks of becoming homeless, unemployed or in contact with the criminal justice system are also reported (Pecora et al., 2005). These challenges are further compounded by a reduction in access to support services as care leavers exit child care services. Furthermore, there is a reported mismatch of psychotropic medication used to address mental health needs involving over and under use by care leavers (Raghavan & McMillen, 2008). Targeted services aimed at preventing a deterioration in the mental health of care leavers with identified mental health problems are crucial at this time of transition. Several studies also highlight the need to involve care leavers in decisions regarding their post-care lives and their mental health care (Cashmore & Paxman, 2007; VOYPIC, 2013). Improvement in ease of access to appropriate mental health services during in-care and post-care periods was also highlighted (Mullan et al., 2007; Vinnerljung et al., 2006).

Despite poorer mental health outcomes highlighted across a range of studies, the review also identified some factors related to successful outcomes for the mental health of young people leaving care. Those who leave care at an older age and access continued support services have extra time to adjust and develop their resilience and ability to cope with the new demands of independence (Cashmore & Paxman, 2007; Daining & DePanfilis, 2007; Dixon et al., 2006; Fowler et al., 2011). Policies

and services which are most likely to promote emotional wellbeing are those which enhance life skills including how to: pursue educational pathways; obtain and maintain employment; manage finances; secure safe, affordable housing; and meet the requirements of independent living (Daining & DePanfilis, 2007; Fowler et al., 2011). For care leavers with mental health needs, barriers regarding assessment and access to appropriate treatment need to be addressed (Pecora et al., 2005). The benefit of well-timed, planned and coordinated transitions from care and from child to adult mental health services are emphasised as essential to improving outcomes for care leavers (Brown & Wilderson, 2010; Cashmore & Paxman, 2007; Courtney & Dworsky, 2006; Dixon et al., 2006; Fowler et al., 2011; Lamont et al., 2009; Mullen et al., 2006; Pecora et al., 2005; Scott et al., 2007, 2009).

Across the research reviewed, it is emphasised that policy and practice should consider care leavers as a high risk group for significantly poorer mental health (Vinnerljung et al., 2006). Services, therefore, need to be geared towards meeting the mental health needs of care leavers (Brown & Wilderson, 2010; Pecora et al., 2005) and care planning should include risk reducing and resilience enhancing activities to improve their post-care outcomes (Goldstein et al., 2013; Mullan et al., 2007). It is also important that services are responsive to the heterogeneous characteristics of care leavers with mental health needs including ethnicity, culture and gender (Courtney & Dworsky, 2006; Daining & DePanfilis, 2007; Garcia et al., 2012; McMillen & Raghavan, 2009; Yates & Grey, 2012).

## **SUMMARY**

The review of literature identified a very limited evidence base relating to disabled care leavers and studies that have been undertaken are predominantly qualitative and small-scale. There is a much larger body of research on the mental health needs of care leavers which is generally large scale, quantitative and predominantly American. As there is an absence of research with care leavers who have borderline/undiagnosed impairments, are homeless, are not engaged with services or are from ethnic minority backgrounds, future research should actively seek to include these neglected groups of care leavers.

The empirical research available indicates that care leavers with mental health and/or disabilities face additional challenges in relation to education, health, employment, housing and social support. Higher risks of substance misuse, self-harm, suicide, depression and homelessness are repeatedly cited, alongside difficulties with accessing specialist services and limited co-ordination across child and adult programmes of care. Staying in care longer, having strong social and formal support networks, and accessing education and employment opportunities are critical factors associated with successful transitions from care. Features of effective policy and practice, include:

- Strengths-based, person-centred planning targeting young people's self-determined priorities;
- Planned, flexible and appropriately paced transitions;
- Inter-agency approaches within and across child and adult services;
- Prompt access to mental health services in-care and post-care;
- Opportunities to remain in care until an older age with continued access to support services;
- A focus on resilience, skills development and pathways to education and employment; and
- Support to secure safe, affordable housing and manage finances.

Finally, as the review highlighted ongoing structural and organisational challenges, there is an imperative to ensure service planning and policy directives relating to service provision for care leavers are informed by research.

## 2.0 METHODOLOGY

This section describes the methodological approach for the study beginning with an outline of definitions and inclusion criteria. The data collection process for the profiling survey and the qualitative case studies is then described in detail, including the peer research approach to interviews with care leavers.

### 2.1 DEFINITIONS AND INCLUSION CRITERIA

The study was guided by the definition of disability provided by the UN Convention on the Rights of Persons with Disabilities [UNCRPD] (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.”* This definition is in accordance with Section 75 of the Northern Ireland Act (1998) and the principles of critical disability studies by recognising both the experience of impairment and the impact of disabling barriers in society on equality of opportunity. This definition of disability is also inclusive of mental health and/or intellectual disabilities which are the focus of the study.

Whilst varying definitions of mental health and/or intellectual disability exist across Trust areas and service boundaries, often linked to eligibility criteria for access to services, the study is focused on care leavers who have been assessed as:

- Having an intellectual disability<sup>4</sup>, a mental illness or autistic spectrum disorder (ASD)
- OR
- Either awaiting or receiving disability or mental health services on the grounds of intellectual disability, mental health or ASD related needs.

Mental health and intellectual disability (including ASD) are included because these impairment types are most prevalent in the leaving care population, are often co-existing and relate to the remit of the study’s funder (under the Bamford Review). Care leavers with mental health and/or intellectual disabilities who also have other impairments (e.g. physical/sensory) are included in the sample.

The study uses the legal definition of care leaving under the Children (NI) Order 1995 and the Leaving Care Act 2002. ‘Eligible’ children are aged 16 and 17 and have been looked after at least 13 weeks since the age of 14 and are still looked after. They become ‘relevant’ children when they leave care if still under 18. ‘Former relevant’ and ‘qualifying’ care leavers have left care and are aged between 18 or 21 (or up to age 24 if in education/training). The upper age limit of 25 years allows for exploration of gradual transitions well into young adult life (Stein and Munro, 2008). It also recognises that many disabled young people leave care/school at an older age (Rabiee et al., 2001).

The study excludes care leavers who are only been looked after due to short breaks usage. This group of care leavers are excluded because: under current regulations these young people do not meet the leaving care criteria; they may only be looked after for short periods of time; and they are not classified as looked after children in other UK jurisdictions (Rabiee et al., 2001). The research team consider this to be a separate group who would merit a study focused on their particular experiences.

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<sup>4</sup> This includes mild, moderate or severe levels of intellectual disability.

Ethical approval for the study was granted in advance by the Office of Research Ethics Committees NI (ORECNI) and the School of Sociology, Social Policy and Social Work at Queen's University Belfast. Research Governance procedures were then followed in the HSCB and in each Trust, in accordance with the Data Protection Act (1998).

## **2.2 PROFILING SURVEY**

The first stage of empirical data collection for the study involved a survey completed by social workers working in all of the 16+ teams across NI to profile the population of care leavers with mental health and/or intellectual disabilities. This section of the report will summarise the survey aims, method and findings.

The key objectives were to:

- Examine the characteristics of the population of care leavers with mental health and/or intellectual disabilities in NI;
- Investigate their care leaving experiences and access to services; and
- Establish baseline data on this population to inform practice and further research examining adult pathways and longer-term outcomes in adult life.

### **2.2.1 The Survey Approach**

A follow-up survey linked to the Health and Social Care Board's (HSCB) regional corporate parenting data return on care leavers was conducted to profile the characteristics of the total population of care leavers with mental health and/or intellectual disabilities in NI on 30<sup>th</sup> September 2013. Existing annual Departmental statistical reports provide total numbers of care leavers but do not account for duplication or allow for cross comparison across disability, needs or circumstances. This follow up survey allows for the collection of data at an individual care leaver level which facilitates disaggregation of data and further analysis.

In order to facilitate the survey, the research team worked with the senior information officer in the HSCB responsible for the DSF return to amend the disability question (and associated guidance) in their bi-annual request for information on care leavers from Trusts to:

- a) Include a category for young people with autistic spectrum disorder in the list of impairment types; and
- b) Include care leavers who have been assessed as having a disability or mental illness as well as those who are awaiting/receiving disability or mental health services.

It should be noted that the addition of a separate category to record ASD is an achieved positive impact of the study. It has been maintained for subsequent data returns and facilitates, for the first time, the identification and recording of care leavers with ASD in the statistical return. Previously, the HSCB were unsure if they had captured this population as they may or may not have been recorded in the 'other' or 'learning disability' categories.

With the amended disability question and associated guidance in place, the HSCB then asked each of the five Health and Social Care Trusts to hold a list of all care leavers returned under the intellectual disability, ASD and mental health questions in their statistical data return for 30<sup>th</sup> September 2013 to

facilitate the survey. Trusts were asked to compile this list with social care numbers, dates of birth and the named social worker for each care leaver. This list was then checked for accuracy through consultation with Team Leaders from 16+ services who complete HSCB data returns and individual social workers who were then asked to complete a profiling online survey for care leavers on their caseloads.

### **2.2.2 Designing and Administering the Questionnaire**

The online survey was facilitated by the Qualtrics software which was password protected and, once complete, downloaded directly to SPSS software, ensuring a secure and straightforward process. Although social workers were advised that the survey could be made available in hard copy, all of the social workers chose to complete the survey online. Data was held securely on a password-protected computer. Although service related numbers (e.g. health or social care numbers) and dates of birth were collected to facilitate sample selection for the case study stage of the project, the research team had no means of identifying young people from the information provided.

The questionnaire design ensured that it gathered comprehensive information whilst also being relatively quick and easy for social workers to complete, without the need to consult case files. Inclusion criteria were checked in the first two sections of the survey with social workers selecting at least one criterion in relation to the young person's leaving care status and impairment type. The layout of the questionnaire was such that sections could be skipped if they were not relevant to the experience of particular children and young people (for example, siblings or specific services used). The questionnaire was piloted with two social workers and two social work managers working in 16+ services. Their feedback confirmed it took between 10-15 minutes to complete and had a user friendly format. A few suggested amendments to layout were suggested and these changes were incorporated into the final version.

There were two key stages in the administration of the survey: accessing anonymised lists of care leavers meeting the study criteria from the DSF return; and completion of the survey by social workers. Although the research team were supported by the HSCB to access the anonymous lists of care leavers based on the 30 September 2013 return, only two of the Trusts were easily able to track details for young people included in the data return when requested. In other Trusts, gathering this data was an additional task as a retrievable list had not been compiled at the time of the data return. Whilst this required more time, it also offered an opportunity for all Trusts to check their data return for accuracy and identify any inaccurate or missing data. Between October-December 2013, Trusts were asked to check their return and compile lists of care leavers to facilitate the survey. Alongside this process, some Trusts were also finalising their honorary agreements for the research team to undertake the research. In January 2014, lists were finalised with the access to data commencing by February 2014.

Once lists were received from Trusts, they were checked for duplicates and then compared with the DSF return to identify any categories with a lower than expected return. In such cases, the research team asked the manager in the relevant Trust to check the accuracy of the return and consult with staff regarding any missing cases. This process of checking the data and providing additional information on missing cases continued in the last Trust (BHSCT) until September 2014. At this stage, surveys were complete in most other Trusts, however, survey completion continued in the BHSCT until December 2014.

In each Trust, managers encouraged staff to complete the survey and the researcher met with teams to demonstrate the online survey and ensure all questions were clearly understood. Social workers

were given two weeks to complete surveys unless a longer timescale was required due to leave or particular demands on the team at that time. When the agreed time scale lapsed, the researcher checked the number of returns on the online system and followed up with individual social workers or Team Leaders on any missing surveys. The vast majority of professionals who completed the survey were social workers (92.7%), with 5.1% being senior social workers and 2.2% being the young person's personal adviser.

A total of 314 completed surveys were returned (134 in the disability category and 180 in the mental health category), comprising 23.4% of the total population of care leavers. By comparison, the DSF report for 30 September 2013 identified 179 care leavers in a disability category and 225 with mental health needs (n=404), comprising 30.2% of the total population of care leavers.

The 6.8% difference is likely to be due to the fact that the DSF return does not account for those with co-existing mental health and disability and, therefore, counts some young people more than once across these impairment categories. In addition, the DSF return includes ADHD within the ASD category (in the study survey this was an additional need) although it is not clear how this was interpreted by those completing the DSF return as the numbers remain low.

Given these variations in definition across both datasets, our overall sample of 314 disabled care leavers (including those with disabilities and mental health needs) is a very sound response rate indicating that the survey was successful in capturing the population of disabled care leavers in NI.

In terms of response rate by Trust, slightly higher numbers are recorded for each Trust with the exception of the Belfast Health and Social Care Trust (BHSCT) (19% of survey returns were in this Trust compared with 30% of the DSF returns). Lower numbers of care leavers within the BHSCT could reflect a lower survey response rate in that Trust but could also reflect a higher level of co-existing mental health and intellectual disabilities amongst the Trust's population. Overall, the challenges for some Trusts in accessing accurate data on the population of care leavers indicates a need for a more robust method for collating and maintaining records on this population.

### **2.3 CASE STUDY METHODOLOGY**

The final stage of the study used a case study design to focus on care leavers' experiences and perspectives and those of their social workers/personal adviser (PAs) and, where appropriate, their carers and birth parents.

The objectives for the case study aspect of the project were to:

- Explore how care leavers with mental health and/or intellectual disabilities perceive their experience of transition and their support needs in young adult life;
- Examine the interface of current service arrangements and organisational arrangements and procedures within Trusts impacting on services for these care leavers;
- Investigate how well the particular needs of these care leavers are met, or could be met, within a multi-disciplinary context; and
- Identify any examples of best practice in meeting the needs of these care leavers.

As the study sought to explore the experiences of young people from varying perspectives and to further examine the hows and whys of the survey findings, a case study design was appropriate (Yin, 2003). The case study approach allowed for the consideration of contextual conditions (including the service context and the unique circumstances of individual young people) and exploration of complex



and multiple situations across the domains of youth leaving care, mental health and intellectual disability (Flyvbjerg, 2006). The case study methodology also enabled the research team to gather data from a variety of sources and to converge the data to illuminate the care leaving experiences of each young person (Baxter & Jack, 2008).

The case studies involved two stages. Firstly, young people’s social work case files were read by the professional researcher and relevant information relating to their transitions into, through and from care were recorded for analysis and to help prepare for the interview with the care leaver. Secondly, a semi-structured interview with each young person was carried out by a peer researcher and/or a professional researcher at three separate points over the course of the study (the mid-point mostly by telephone interview). These interviews were undertaken over approximately 18 months for an in-depth examination of care leavers’ views and to track their transition experiences as they progressed into young adult life. Finally, key people in care leavers' lives were interviewed by the professional researchers; including current or former carers, social workers or PAs, and, where appropriate, their birth parent.

### 2.3.1 Sampling of Case Study Participants

A total of 31 young people took part in the case studies. As outlined in the table below, these participants were selected from the profiling survey’s sampling frame using a stratified sampling process to ensure inclusion of as broad a range of characteristics as possible across: impairment type; gender; age; length of time in care; type and number of placements; and Trust area.

CHARACTERISTICS OF SAMPLE OF YOUNG PEOPLE	
Trust	BHSCT (n=8); WHSCT (n=5); NHSCT (n=8); SEHSCT (n=5); SHSCT (n=5)
Impairment type	Single impairment type: ID (n=5), MH (n=12) ASD (n=2) Co-existing impairments: ID+MH (n=4); ID+ASD (n=5); MH+ASD (n=3)
Gender	Male (n=14); female (n=17)
Age	16-17 years (6); 18-19 years (10); 20-23 (15)
Length of time in care	1yr or less (n=1); 2-3yrs (n=6); 4-5yrs (n=7); 6-10yrs (n=6); 11+yrs (n=11)
Main type of placement whilst in care	Home with birth family (n=1); Non-relative foster care (n=15); kinship care (n=2); Children’s residential home (n=8); Specialist residential care (n=1); specialist hospital (n=4)
No. of placement moves while in care (<18 years)	None (n=7); 1-2 (n=9); 3-4 (n=9); 6-9 (n=2); 10-14 (n=2); 15+ (n=2)

Table 1: Characteristics of sample of young people

### 2.3.2 Recruitment and Gaining Consent

The social worker (16+ or disability services) of each young person was contacted to discuss the young people’s potential participation in the study and determine if there were any circumstances in which participation could adversely affect them. A small number of young people were in the midst of ongoing difficult circumstances or mental health crises and, in these cases, researchers were advised not to pursue consent processes. For example, one young person had experienced a recent bereavement which led to a deterioration in mental health and another young person had been

hospitalised following multiple suicide attempts and in both cases there were concerns that interviews exploring family relations and leaving care would cause further undue distress. Some other young people initially selected to take part but could not be contacted again as they had disengaged from social services and/or had become homeless and no follow up contact details were available.

Packs containing information about taking part in the study were sent to social workers who agreed to share the information with potential participants. Accessible leaflets for young people with varying abilities were developed in conjunction with Mencap who were also involved in the production of a DVD which featured the research team and provided an audio-visual version of the information contained in written formats. Young people were encouraged to watch the DVDs and/or read the information provided to help them to decide if they would like to take part in the study.

Young people indicated they wished to take part in a number of ways. A few posted completed reply slips to the research team and some contacted the researchers directly by telephone, text or email message to discuss the study further. However, in most cases, young people agreed to their social worker sharing their names and contact details with the researcher who then contacted the young people to arrange interviews. Two young people joined the study following their involvement in a separate study on disabled children in care, as they had become leaving care age and were happy to stay involved with the research team and participate in further interviews on leaving care. For young people with more severe levels of intellectual disability, their social worker or keyworker assisted with arrangements to meet the young person with consent being sought at the first meeting and viewed as a continual process. Young people were advised they could stop the interview at any time using a stop sign provided or by telling the researcher they wanted it to end. The researcher also responded to any verbal or non-verbal cues from young people that indicated they were unsettled during the interview and checked whether they were happy to continue or wished to end the interview.

When young people had agreed to participate in the study, their social worker/PA was also invited to participate in an interview about the case and their wider experience of supporting care leavers. If young people were still in contact with their carers (some were still living with carers and others remained in close contact with them), carers were also invited to participate in an interview. Finally, if birth parents still played a major positive role in the young person's life (some were living with birth parents), they were also invited to participate in an interview.

Written consent was gained from all participants at the beginning of interviews. Participants were reminded that consent was an ongoing process from which they could feel free to withdraw at any time. Additionally, all young people consented to researchers reading their case files for the purposes of the study.

### **2.3.3 Case File Reading**

Young people's care files were read, from which relevant information was recorded on a pro forma. Areas of interest were: care status; impairment; significant events leading to entry to care; significant in-care events including placement changes; services used; engagement in education or employment; and post-care circumstances. All files were read in social work offices and no material contained within files was copied or removed from these buildings.

Files were generally extensive and detailed. The number of files available for a young person was dependent on length of time in care, number of placement moves and complexity of the case. In some cases of young people who had transferred across LAC, children's disability, 16+ and adult services,

their earlier files were unavailable. Additionally, the files of one young person were not accessible due to an ongoing investigation relating to the young person.

Case files provided essential background information on the case and helped to track the young person's journey into care, through care and post-care. Young people's contacts with various professionals and services were documented, as well as the complexity of their needs over time.

#### **2.3.4 Peer Research Approach**

The case studies incorporated a peer research methodology whereby young people who were care-experienced were trained to interview care leaver respondents either on their own or alongside the professional researcher.

The peer researcher recruitment process began in October 2013 and continued until February 2014. Advertisements of the application form and job description, which included brief information on the role of the peer researcher and the level of commitment expected of successful applicants, were widely circulated throughout Northern Ireland by the study's key partner organisation, the Voice of Young People in Care (VOYPIC) and 16+ teams. Care experienced students enrolled in third level education were also directly informed about the opportunity via email from the two coordinators for student outreach for care leavers at both Universities in NI.

Overall, 21 applications from care experienced young people aged between 18 and 25 years were received. All those who applied were offered interviews, however, four young people later declined an interview and five young people did not attend for interview. Of the 12 young people who were interviewed over four interview sessions in Derry and Belfast, 10 were offered a peer researcher position pending successful completion of mandatory training. The two young people who were unsuccessful performed poorly across most areas of the interview and were given feedback on areas for improvement before being offered a second opportunity for interview which both young people declined.

The 10 applicants who were successful in the recruitment process were aged between 20 and 24 years with a range of care experiences. Most were motivated by a desire to help other young people leaving care and had knowledge of issues affecting care leavers, particularly in relation to support needs, vulnerability and mental health challenges. In contrast, they had more limited experience of disability issues. Three successful applicants were enrolled in, or had completed, third level education courses during which they had undertaken research skills training. The others were completing college courses or were not engaged in education, training or employment.

Two orientation workshops were provided for the 10 successful candidates in February and March 2014 at QUB and attended by the research team, peer researchers, other academics engaged in peer research and representatives from voluntary organisations working with peer researchers. Following these orientation workshops, four applicants withdrew from the process either because of new training or employment commitments or, due to added insight into the role of a peer researcher, they decided not to proceed with the training.

The six successful candidates were then required to participate in a compulsory five-day intensive training programme in March and April 2014. Training was delivered by members of the core research team and voluntary organisation partners in the study (VOYPIC, Mencap and Praxis Care). Each of the five training days focused on a particular aspect relevant to the peer researchers' involvement in the study: the research context; mental health awareness; disability awareness; ethics; and interview

skills. Various training delivery techniques were employed such as presentations, group activities, discussion sessions and role play. Peer researchers also had the opportunity to influence the design of interview schedules and to script an introduction and description of the peer research role to be used at the start of interviews.

Of the six young people who proceeded to training, one applicant failed to attend two days of training and, as a result, effectively withdrew from the process. In total, five young people completed the initial training programme. However, one young person then withdrew from the study to pursue a college course and, during first round of interviews with care leavers, a further young person exited the project due to personal circumstances. A new peer researcher was recruited via VOYPIC and trained midway through the project to replace this person who left during fieldwork.

Following in-depth discussions about levels of support peer researchers felt they would require to carry out initial interviews, it was jointly decided each peer researcher would be supported by a professional researcher from the team for the first round of interviews. Mid-point interviews were mostly conducted by telephone by the peer researcher. For final interviews, peer researchers discussed each case with the researcher to reach a decision on whether to interview alone or be accompanied by the researcher again.

Ongoing support was offered to peer researchers throughout the study by the research team. Peer researchers were also provided with named contacts from VOYPIC as another source of support, external to the core research team. However, they preferred more informal direct support from the researcher before and after their interviews. Throughout the study, peer researchers also participated in further team reflection workshops and refresher training and a formal course on use of the MAXQDA computer package for qualitative data analysis in July 2015.

The peer research methodology was formally, independently evaluated and further details are available in the evaluation report (Dowling, 2016) on these grounds was small. Overall, the evaluation highlighted the added value of the peer research approach for peer researchers, participants and the research study. Key benefits for the study included: a high retention of participants over the period of the study which was linked to the rapport developed with participants; an informal style of interviewing which enabled open and in-depth responses from participants; strong rapport and empathy between peer researchers and participants which improved the quality of data collected and participant experience; the insight and integrity that peer researchers brought to the analysis of data; and the powerful presentation of the research findings by peer researchers to various stakeholder audiences. In addition, peer researchers felt they benefitted personally and professionally from their role on the study as they developed their self-confidence, learnt new professional skills, gained work experience and established new friendships with other peer researchers. Unexpectedly, their role as peer researchers had also helped the peer researchers to re-frame their own care experience and informed their decisions about their further study and future careers, for example, pursuing careers in social work or engaging in further research activities.

Whilst there were many benefits to the peer research approach, it is also important to note that there were additional responsibilities for the professional research team in terms of training and support for peer researchers. There were practical challenges in terms of researcher time, transport for peer researchers and the planning and coordination of interviews to ensure they were scheduled at a time that suited the participant, peer researcher and accompanying researcher, particularly as peer researchers were also engaged in college courses or employment. A final challenge for the project, was the emotional impact on peer researchers of hearing care leaver stories and witnessing their daily living conditions alongside a reluctance to say goodbye after final interviews with particular

participants. Peer researchers indicated that future research projects could link with organisations such as VOYPIC to build in opportunities for peer researchers to have further contact with participants after the end of the study in new roles as mentors or as another source of informal support. However, there are clearly ethical and training issues related to such ongoing roles which would need to be carefully considered by peer researchers, participants and partner agencies.

### 2.3.5 Case Study Interviews

As most young people were interviewed up to three times, a total of 131 interviews were held during the course of the study. The following table provides the numbers of interviews across each participant group.

RESPONDENT		NUMBER OF INTERVIEWS	
Young people (n=29 <sup>5</sup> )		79 (2x1 interview; 4x2 interviews; 23x3 interviews)	
Birth parents (7)		6 (inc. one co-interviewed couple)	
Foster carers (2 kinship, 12 non-relative)		12 (inc. two co-interviewed couples)	
Residential key workers (3)		3	
Social workers (28)		28	
PAs (3)		3	
<b>TOTAL NUMBER OF INTERVIEWEES</b>	<b>84</b>	<b>TOTAL NUMBER OF INTERVIEWS</b>	<b>131</b>

Table 2: Total number of interview respondents

The interviews were semi-structured in style which meant that key themes could be explored relating to the research questions whilst participants could also discuss their own unique experiences and identify new themes relevant to the study. With prior agreement, all interviews were audio recorded and transcribed for analysis.

For young people with more severe intellectual disabilities, the researchers used a shorter version of the interview schedule that covered the main interview topics but was presented in a booklet format with accompanying pictures and keywords to make it more accessible. Researchers also provided feelings cards illustrating a range of emotions. In addition, several participants had a carer or family member present to support them to participate in the interview.

Only two young men living in specialist adult residential care did not provide interview data. Strict routines were in place for both young people in their care settings and, to avoid an escalation in challenging behaviours, unfamiliar people were rarely introduced to their care environment. The researcher, therefore, worked closely with their key workers to establish a suitable time to visit these young people and, when possible, participated in an activity with them assisted by their key workers. It is always challenging to design a research approach that facilitates the inclusion of all young people with various levels of impairment and in a range of care settings (Kelly, 2007; Aldridge, 2014). It may have been possible to gather further data directly from these young people in a different care environment or by spending more time with them to build a rapport and establish a channel of communication using alternative methods (Nind, 2009; Walmsley & Johnson, 2003). Such approaches were beyond the time and resource constraints of the present study, however, we recommend further research focused on care leavers with severe and profound levels of impairment with bespoke approaches to facilitate the participation of individual young people. For our study, although we could

<sup>5</sup> Two young people did not participate in an interview.

not conduct an interview with both young people, we felt it was still important that they were not excluded from the research and had an opportunity to meet and interact with the researcher. In addition, the parents, key workers and social workers of both these care leavers took part in interviews for the study and provided information about their experiences to add to data collected from their case files.

The first round of interviews with young people took place mainly in their own homes, except for two which took place in a social work office and one which took place in a private room at the university. Peer researchers were encouraged to take the lead on interviews with the professional researcher providing a support role in making sure relevant consent forms were signed and the voice recorder was operating. The professional researcher also, where necessary, contributed to the interview by probing on more difficult topics. Safety protocols for the researchers were established in advance of fieldwork which included a range of measures, such as, joint interviewing in pairs when the research team had been alerted to risk concerns and clear systems for reporting concerns about risk of harm through the Principal Investigator and agreed statutory channels. All peer researchers completed training on these safety protocols before fieldwork commenced and any concerns about risks were discussed with peer researchers in briefings before individual interviews.

The second round of interviews was carried out approximately six months after the initial interview, mostly by telephone. In cases where face to face interviews were required due to communication styles, the peer researchers met with young people again supported by the professional researcher, as necessary. The purpose of these interviews was to monitor any changes in the young person's life since their first interview. Two young people had disengaged from social services by this stage and follow up interviews were not possible as they were not contactable.

The third round of interviews occurred approximately six months later and were mostly face to face in the young person's home. Seven participants were interviewed by the professional researcher alone. Four of these had been interviewed/observed by the professional researcher at earlier stages of the study and three were interviews previously undertaken by the peer researcher who later exited the study and it was deemed inappropriate to introduce an unfamiliar peer researcher for the final interview.

Of the remaining 22 final interviews, peer researchers completed 13 alone and 9 were co-produced with the professional researcher. Decisions as to whether participants should be interviewed solely by the peer researcher or co-produced were reached jointly and based on careful consideration of the following issues: gender, risk, dynamic of having others present during interviews, and the communication needs of participant. At this final stage of interviewing, co-produced interviews were very much led by the peer researchers with professional researchers taking a minimal role, mostly as back up support. On reflection following interviews, both peer researchers and professional researchers agreed that decisions to co-produce or interview alone had been made appropriately.

The purpose of these final interviews, in addition to monitoring changes in the young people's circumstances, was to capture their reflections on leaving care and available services. They were also asked if they had any advice for other care leavers or recommendations for policy makers and practitioners working with care leavers.

Interviews with carers, parents and professionals were conducted by the professional researchers. Interviews with parents and carers took place in their homes and professionals were interviewed at their place of work. These interviews were usually conducted after the young person's first interview

and explored their perspectives on the experiences of care leavers with mental health and/or intellectual disabilities and how well their support needs were being met.

## **2.4 DATA ANALYSIS**

Survey data analysis began by running frequencies and cross-tabulations to identify findings relevant to the full range of questions. Relationships between different sub-groups of disabled care leavers were identified by conducting cross-tabulation of combinations of variables (for example, impairment and care leaver status) and testing for significance and odds ratios.

In order to facilitate the analysis of qualitative interview data, recordings were transcribed and uploaded into MAXQDA, a qualitative data analysis software package that facilitates thematic analysis of qualitative interview data (Kus Saillard, 2011). Validity and reliability were promoted, and researcher bias reduced, by a process of two professional researchers independently thematically coding two transcripts from the first round of interviews to establish an initial coding framework based on comparison of their joint analysis of the data. The peer researchers then collaborated with the professional researchers to test the coding framework by jointly coding further transcripts at analysis workshops. Having agreed the final coding framework, the professional researchers then completed analysis of the remaining interview transcripts. As peer researchers were not involved in the interviews with professionals, carers or parents, the professional researchers conducted analysis of this interview data again using MAXQDA to inductively identify themes and jointly confirm codes for the systematic analysis of interview data.

The professional researchers then used the coded data in MAXQDA to write up the study findings. During the write up, a draft of the report was shared with the peer researchers and during a half-day workshop the peer researchers collaborated with the professional researchers on the content of each section of the report. At this workshop, peer researchers reflected on the experiences of each young person they had interviewed and checked to ensure that all key findings in relation to each young person was included in the write up of the findings. This process helped to ensure that the professional researchers had not missed important details of young people's experiences, particularly those the peer researcher had interviewed alone, and also provided an important opportunity for the peer researchers to influence how the findings would be presented in the final report.

## **2.5 STUDY LIMITATIONS**

It is important to note that the study only captures care leavers who were known to Trusts on 30 September 2013, therefore, those who had already ended contact with services by 30 September 2013 could not be included. These young people may have included those who are most vulnerable care leavers and hardest to reach as they exited services early.

In addition, whilst every effort was made to ensure completion of surveys and the number of completed surveys indicates a very strong rate of response, it is possible that some young people eligible for the study were not included in the data return from Trusts.

As is the case in most qualitative studies, the case study approach only involved a sample of young people leaving care and, therefore, cannot claim to be representative of the experiences of the entire population. The research team, however, made much effort to include a wide range of young people with varying experiences of care, impairment and post-care services. As a result, the findings reported

highlight the variety of experience within this population of care leavers and common themes across their experiences of leaving care.

Some young people who were selected from the sampling frame to take part in case studies did not participate because they were not contactable, their social worker did not deem it to be in their best interests or they did not wish to participate. In addition, two young people disengaged after initial interviews. In all of these scenarios, important data relating to the most vulnerable care leavers may have been missed. However, the number of young people who were excluded from the study on these grounds was very small and the findings from the interviews with participants captured the views of some young people who were considered among the most vulnerable on social workers' caseloads.



### 3.0 PROFILING SURVEY FINDINGS

This section of the report presents the profile of disabled care leavers in NI based on the findings of the survey completed by social workers, including their demographic characteristics, their family background and contact and their range of impairment experiences. The legal status of disabled care leavers, their access to services and issues relating to safeguarding and risk-taking behaviours are also discussed. Finally, living circumstances, income levels, engagement in education, training or employment and unmet needs are considered. Throughout the report, where relevant, the findings will be compared with population data and data from the DSF statistical return on all care leavers for the same period (at 30 September 2013) (HSCB, 2013).

#### 3.1 DEMOGRAPHIC PROFILE

Just over half (52.2%) of the study sample are male, with 47.8% being female, reflecting similar figures in census data on the gender of the population aged 16-25 years in NI (NISRA, 2014) and DSF return for the overall care leaver population (HSCB, 2013).

In the survey population, ages range from 16 to 22 years, with a mean age of 18. Just over one fifth (21.3%) are aged 16, almost half (47.8%) are aged 17-18 years, over one quarter (28.7%) are aged 19-20 years; and a very small proportion (2.2%) are aged 21+ years.

The vast majority of the survey sample (96%) are white Northern Irish or white other and born within Northern Ireland (81.2%), with a smaller proportion being born in the wider UK (6.3%) or Southern Ireland (3.5%). The majority of young people are either Protestant (47.8%) or Catholic (45.2%), and a smaller proportion having no religious affiliation (4.8%) or 'other' religious affiliations (1.3%), including Muslim, Seventh Day Adventist and Jehovah Witness (religious affiliation was unknown for two young people).

Only 12.1% (n=38) of the survey population are parents (similar to the prevalence of parenting in the wider leaving care population, 11%), while 5.1% (n=16) were pregnant at the time of data collection. The majority (81.6%) of parents have one child, six parents have two children and one has three. The majority (63.2%) of those who are parents are female and 40.7% of those who are parents/pregnant are under the age of 18 (at the time of the survey). Less than half (47.4%) of parents are living with their children.

#### SUMMARY

- The age of disabled care leavers peaks at 17 years and the stark decrease in numbers in the older age ranges indicates that some disabled care leavers may be exiting leaving care services by the age of 20 and an ongoing focus in 16+services on younger care leavers with a potential gap in provision for vulnerable care leavers over 21 who have continuing needs.
- There are no major differences between the survey population and the wider care leaver population in terms of gender, religion or ethnicity.
- There are similar rates of parenting compared to the wider leaving care population with less than half of those who are parents living with their children.

### 3.2 RANGE OF IMPAIRMENT EXPERIENCE

More than half of the survey sample are in the mental health category (57.3%) and 42.7% in a disability category. Those with intellectual disability (including specific diagnoses, such as Down's syndrome, and less specific diagnoses, such as global developmental delay) form the largest group within the disability category, at just over a fifth (21%) of the overall study sample. The other main impairment type within the disability category is ASD (including Asperger's syndrome), forming 12.1% of overall study sample. Smaller numbers are reported in the 'other' impairment category (which includes physical and sensory impairments), 3.8% of the overall study sample; and multiple impairment category (those with three or more impairment types), 5.7% of the overall study sample.

The DSF return data shows similar trends in the prevalence of impairment overall. There are slightly lower numbers in the ASD and 'other' impairment categories in the study sample, however, this is likely to be due to variance in definitions across the datasets with the DSF including ADD/ADHD in their definition of ASD and not recording multiple impairments.

It is important to note that 27.3% (n=18) of those in the intellectual disability category also have a mental health need. In addition, almost two thirds of young people in the ASD category (60.5%, n=23) also have intellectual disability and/or mental health needs. Overall, almost one fifth of the study sample (18.8%, n=59) have more than one impairment type across the disability and mental health categories. As the DSF return does not allow for the identification of co-existing mental health and disability, these findings are particularly important as they highlight the previously unknown complexity of need amongst the group of disabled care leavers.

There are more females in the mental health category (55%). In contrast, the large majority of those with ASD are male (86.8%) and there are also more males in the intellectual disability category (53%). These figures reflect statistics on children in need in NI where 80% of those with autism are reported to be male, and more males are reported across all disability categories (20% of males having a disability compared with 12% of females in the children in need population) (DHSSPSNI, 2014a: 10). Similarly, Departmental figures on the prevalence of autism in school age children in 2013/14 show that autism was almost five times more prevalent in the male population than the female population (DHSSPSNI, 2014b: 6).

By Trust area, the highest number of care leavers with intellectual disabilities are in the BHSCT and the same trend prevails for those with ASD. The lowest number of care leavers with intellectual disabilities are in the NHSCT and the lowest number of those with ASD are in the WHSCT. The highest numbers of those with mental health needs are in the NHSCT and the lowest number are in the BHSCT.

Of the total 180 young people in the mental health category in the survey (57.3% of overall survey sample), 37.8% have an assessed mental illness and 62.2% are receiving or awaiting mental health services. It is notable that, of those who have been diagnosed with a mental illness (21.7%), more than a quarter (27.9%) have co-existing impairments, most commonly intellectual disability followed by ASD.

Of those with an assessed mental illness, 36.9% were assessed as having a mental illness before becoming LAC and 44.6% after becoming LAC.<sup>6</sup> The majority are diagnosed with depression, followed by anxiety, personality disorder, Post-Traumatic Stress Disorder (PTSD) and schizophrenia. Smaller

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<sup>6</sup> A further 18.5% of social workers stated 'don't know'.

numbers of other mental illnesses are also reported including psychosis, dissociative personality disorder, bipolar disorder and compulsive disorder.

Almost a fifth (19.5%) of care leavers in the survey sample require personal care or a high level of supervision. Within impairment groups, almost one third of those with ASD (29.7%), a quarter of those with intellectual disability (25.8%) and 11.1% of those with mental health require personal care/high level supervision.

A range of other health conditions/needs are also reported for care leavers in the study sample. The three main additional needs are challenging behaviours (32.5%), anxiety (30.5%) and ADD/ADHD (17.5%). In addition, 23.6% are reported to have 'other' conditions, including foetal alcohol syndrome and rare health conditions. Smaller numbers are also reported for specific conditions such as epilepsy or asthma.

Within impairment groups, over a third of those with ASD (36.8%) and those with mental health needs (35%) are displaying challenging behaviour, closely followed by almost a third of those with an intellectual disability (30.3%). The majority are male (60.8%) and two thirds are in the lowest age ranges of 16-17 years. As expected, three quarters of those with anxiety are also in the mental health category (74.7%).

Within impairment groups, just over one quarter of those with ASD (26.3%) or intellectual disability (25.8%) are reported to have ADD/ADHD, compared with only 12.2% of those with mental health needs. The majority of those with ADD/ADHD are male (65.5%). In contrast, the majority of those with anxiety are female (55.8%).

## **SUMMARY**

- Over half of the survey sample are in the mental health category (57.3%); with 21.7% having an assessed mental illness (mostly depression or anxiety), and 35.6% receiving/awaiting mental health services.
- Just over one fifth (21%) have an intellectual disability and 12.1% have ASD.
- Almost one fifth (18.7%) have more than one impairment type across the disability and mental health categories.
- Almost a fifth require personal care or a high level of supervision.
- The number of care leavers in the mental health category is highest in the NHSCT and lowest in the BHSCT, a trend reversed for the disability categories. The lowest number of those with ASD are in the WHSCT and the highest are in the BHSCT. These findings may indicate varying approaches to case ownership across Trusts, for example, in the NHSCT disability teams have lead responsibility for care leaver services for disabled young people however, in other Trusts 16+ teams lead on these cases.
- Males outnumber females across ASD and intellectual disability categories. In contrast, there are more females in the mental health category.
- The three main additional health needs identified are challenging behaviours, anxiety and ADD/ADHD. Almost a third of young people are displaying challenging behaviour, mostly males. The majority of those with ADD/ADHD are also male, however, the majority of those with anxiety are female.

### 3.3 FAMILY BACKGROUND AND CONTACT

Almost one fifth of the study sample (17.2%) have a disabled mother and 7% a disabled father (however, impairment status was unknown for 30.6% of mothers and 50.6% of fathers). Of those young people who have a disabled parent, the most common impairment type is intellectual disability for both mothers and fathers, followed by physical impairment. In addition, the mothers of almost half (47.8%) of young people have a mental health need, and 16.9% of fathers of those with a mental health need.

The vast majority (80.6%) of young people have contact with their mother, though a smaller proportion (57.3%) have paternal contact. Of those with siblings, 89.4% are in contact with their siblings. Grandparents also play an important role with 70.7% in contact with a grandparent. In addition, a small proportion (5.1%) have contact with an aunt or uncle.

Overall, 14.6% of young people have supervised contact and 30.6% have supported contact. Contact was supervised most commonly to support the young person or promote more positive family relationships (particularly for sibling contact) and behaviours. A range of significant people in the young person's life are reported to support birth family contact, most commonly field social workers, foster carers and residential staff. The types of support provided included: arranging contact and providing a venue; providing financial support or transport; and providing emotional support for the young person or family members.

#### SUMMARY

- Almost one fifth have a disabled mother and 7% a disabled father, most commonly intellectual disability. In addition, almost half of mothers of young people in the study sample have a mental health need, and 16.9% of fathers (where known).
- The large majority of young people have contact with their siblings and mother, though a smaller proportion (57.3%) has contact with their father.
- A large number also have contact with grandparents (70.7%) indicating the importance of extended family support.
- Almost one third have supported contact with their birth family and 14.6% have their contact supervised.

### 3.4 CARE LEAVER LEGAL STATUS

Reflecting data on the general population of care leavers (HSCB, 2013), two thirds of young people in the study sample are *Former Relevant* (over 18 and have been eligible and/or relevant young people). More than a quarter (26.8%) are in the *Eligible* category (aged 16-17 and are still looked after) and, of these, 63.1% are under a Care Order and 28.6% are voluntarily accommodated. Only 3.8% are in the *Relevant* category (aged 16-17, are eligible and have left care) and a smaller percentage (2.9%) are *Qualifying* young people (under 21, or 25 if in education or training, and having left alternative/private foster care after the age of 16).

The most commonly cited reasons for entry to care for the study sample are neglect (57.6%), followed closely by parents not coping (46.2%) and emotional abuse (41.4%). Smaller numbers of disabled care leavers had been in care due to physical (17.5%) or sexual abuse (10.8%). A further 'other' category

(13.4%) in the figure below includes very small numbers in care for other reasons such as being an unaccompanied minor or relinquished into care.

Variant reasons for being admitted to care can be observed across the two other impairment categories of mental health and intellectual disability. Whilst neglect is the main reason in both impairment categories, this reason is more common for those with intellectual disability (78.8%) than those with mental health needs (51.1%). Emotional abuse is also more prevalent amongst those with an intellectual disability (54.5% compared with 39.4% for those with mental health needs). Moreover, young people with intellectual disabilities are also more likely than young people with mental health needs to have been taken into care because of sexual abuse although the result is not statistically significant. In contrast, those with mental health needs are three times more likely than young people with intellectual disabilities to have been taken into care because they were beyond parental control ( $\chi^2 (1, N = 246) = 9.937, p < 0.005, \phi = 0.21, OR = 3.32$ ). Interestingly, parents not coping is the main reason for entry to care for those with ASD (55.3%) rather than neglect which was the second main reason (39.5%). Only one young person with ASD features in the physical or sexual abuse categories.

Almost half of the study sample (46.2%) experienced significant placement changes during their time in care with three or more placement moves. Less than a fifth (17.9%) had no placement change whilst almost a third (35.9%) had one to two placement changes. Those with ASD are most likely to have no placement changes whilst those with mental health needs are three times more likely than young people with all other impairments to have six or more placement changes ( $OR = 3.38$ ) ( $\chi^2 (3, N = 312) = 24.606, p < 0.001, \phi_c = 0.28$ ). Indeed, the majority of those experiencing 10+ placement changes ( $n=24$ ) have mental health needs (70.8%) or intellectual disabilities (20.8%).

The majority of the survey sample have been in care for over five years (51%), or 3-5 years (25%), followed by 17.6% being in care for 1-2 years and smaller numbers in care for less than a year. Most of those in care for less than one year are in the mental health category (80%) and aged 17-18 (65%). These findings highlight that some care leavers are late care entrants which brings an added complexity of issues at the point of coming into care.

Of those who have left care, 29.3% left care within the past year whilst 50.9% have been out of care for between one to two years and almost a fifth (19.2%) for three to five years<sup>7</sup>.

#### SUMMARY

- The majority of the survey sample are *Former Relevant or Eligible* care leavers.
- Neglect is the main reason for entry to care for those in the two dominant impairment types, particularly intellectual disability, but not for those with ASD where parents not coping is the main reason. Emotional abuse and sexual abuse are more prevalent amongst those with an intellectual disability. Those with mental health needs are three times more likely to have been beyond parental control compared with those with intellectual disabilities.
- Almost half of the survey sample have experienced significant placement changes during their time in care with three or more placement moves. Those with mental health needs and/or intellectual disabilities are most likely to have multiple placement changes
- Just over half have been in care for over five years and a quarter for 3-5 years. Smaller numbers of those in care for less than a year are mostly in the mental health category and aged 17-18. Of those who have left care, the majority left care more than a year previously.

<sup>7</sup> Data for this survey question was missing for 28.6% of the study sample.

### 3.5 LIVING ARRANGEMENTS

Reflecting similar trends in the DSF return for the general population of those who have left care (relevant, former relevant or qualifying), the most common living arrangements are tenancy with or without housing support<sup>8</sup> (38.3%), at home with birth parent (17.4%), former foster care (GEM) placement (10%), and jointly commissioned supported accommodation (8.7%). The 'other' accommodation category (15.5%) includes B&B, hostel, unregulated placements, parenting assessment units and university accommodation.

The number of young people in the survey sample who are living in former foster care (GEM) placements (10%) starkly compares with the 27% of the general care leaver population in the same category. It is also notable that fewer in the study sample are living informally with relatives/friends compared to those in the general care leaver population (3.9% in the study sample compared with 9% in the DSF return).

Young people with an intellectual disability are most likely to have returned home (26.4%), remained in foster care (17% GEM and 7.5% non-relative foster care) or have moved to jointly commissioned supported accommodation (13.2%); and are least likely to be living in tenancy without support (5.7%). In contrast, those with mental health needs are most likely to be living in tenancy without support (28%), followed by tenancy with support (18.2%) and living at home with a birth parent (15.9%). Overall, young people with intellectual disabilities are two times more likely than young people with mental health needs to have returned home (OR = 1.90). Conversely, young people with mental health needs are six times more likely than young people with intellectual disabilities to be in a tenancy without support (OR = 6.49). Young people with mental health needs who have left care are least likely to be in foster care (4.5% GEM, 3.8% non-relative foster care).

Young people with ASD are most likely to be in tenancy without support (32.0%) and are eight times more likely than young people with intellectual disabilities to be in a tenancy without support (OR = 7.84). None of those with ASD are in jointly commissioned supported living placements. However, following trends for those with intellectual disability, some young people with ASD are also living in GEM placements (16%).

Males are more likely to return home to a birth parent (60%) and females feature most prominently in foster care (66.7% non-relative) and tenancy with support (62.2%). Indeed, males are 1.6 times more likely than females to return home to their birth parent (OR = 1.67). In contrast, females are two times more likely than males to be in non-relative foster care (OR = 2.04) and 1.7 times more likely than males to be in a tenancy with support (OR = 1.77). There are minimal gender differences in tenancy without support and jointly commissioned supported living.

Of all the young people in the survey sample, only 12 are detained in a juvenile justice centre or prison and one in secure care. This is the category with the largest gender difference where ten of these thirteen young people are male. The majority of these young people (11 out of 13) have mental health needs.

Overall, 5.4% of young people are living in specialist accommodation. Seven young people (four male and three female) are living in hospital with three aged 16-17yrs and four aged 18-21yrs. Six of these

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<sup>8</sup> There are a range of possible reasons for young people not receiving support with housing including: refusal to engage with services, living independently or managing well on own without additional support.

young people have mental health needs, co-existing with intellectual disability in two cases, and one with ASD and intellectual disability.

Three young people (all male) are living in a residential school (all with intellectual disability and two with co-existing ASD); and six (three males and three females) in a specialist child or adult residential placement (all with co-existing mental health and/or intellectual disabilities or ASD). Two of those in the latter category are placed out of jurisdiction in England as no placements are available in NI to meet their complex needs.

Over three quarters of the study sample (76.4%) are reported to be receiving assistance with accommodation and maintenance from 16+ services. Those with mental health needs are most likely to receive assistance with accommodation and maintenance from 16+ services (78.9%), followed closely by 71.1% of those with ASD, compared with 68.2% of those with an intellectual disability.

Overall, 15.9% of the study sample have access to a floating support worker to assist with housing, with the majority (74%) of these in the mental health category and living in tenancy arrangements.

#### **SUMMARY**

- Young people who had left care were mostly living in tenancy arrangements followed by living at home with a birth parent.
- In comparison with trends in the wider care leaver population, fewer young people in the survey sample remain in former foster care or live informally with relatives/friends.
- Those with intellectual disabilities are most likely to return home, remain in foster care and be in jointly commissioned support living.
- Those with mental health needs or ASD are more likely to be in tenancy arrangements without support.
- Males are much more likely to return home to a birth parent and females are more likely to remain in foster care or move to a tenancy without support.
- Males, mostly with mental health needs, far outnumber females in the juvenile justice/ prison settings and residential schools.
- A small number living in specialist care settings, such as hospital or specialist residential care, have multiple and complex needs, sometimes requiring placements in England as no services are available in NI to meet their complex needs.
- The majority of the study sample are receiving assistance with accommodation and maintenance from 16+ services, mostly those with mental health needs and those living in tenancy arrangements. Similarly, those accessing floating support (15.9%) are mostly in the mental health category and in tenancy arrangements.
- Those with an intellectual disability are least likely to receive assistance with accommodation and maintenance from 16+ services, with almost a third of young people with an intellectual disability (31.8%) not receiving these services.

### **3.6 LEAVING CARE SUPPORT**

Just over two thirds of young people (67.2%) are in receipt of 16+ social work services, with over half being male (54%) and 46% female. Most have contact with their named social worker on a monthly (36.9%) or fortnightly (21.5%) basis. The main reasons reported for young people not having a 16+ social worker are: the young person aged out of service; adult services are now leading; or the young person refused to engage.



Young people with mental health needs are almost two times more likely to have access to 16+ social work services than young people with intellectual disabilities ( $\chi^2 (1, N = 246) = 3.937, p < 0.05, \phi = 0.14, OR = 1.88$ ). Just over half of those with ASD (52.6%) and 56.2% of those with an intellectual disability are accessing 16+ social work services ( $\chi^2 (N = 314) = 16.276, p < 0.005, \phi_c = 0.23$ ).

A third of those aged 16 (32.8%) and 18 (33.8%) and a quarter of those aged 17 (25.6%) are not accessing 16+ social work services. This gap widens for those in the older ages with more than half of those aged 20 (57.1%), 60% of those aged 21 and none of those aged 22 accessing 16+ social work services, indicating that 16+ case closure dramatically increases as young people reach the age of 20.

The vast majority of young people (96.5%) have a completed needs assessment and a pathway plan (94.9%). The majority also keep in touch with their social worker or personal adviser (94.3%) and have general assistance (93.9%). A smaller proportion of young people have assistance with employment (66.9%). The main reasons for not having assistance with employment are: assistance not required (n=23), still at school (n=21) or refused to engage (n=15).

However, variations in access to assistance with employment across impairment categories can be noted. Almost three quarters (73.4%) of those with mental health needs access assistance with employment and 63.2% of those with ASD. However, only 57.6% of those with an intellectual disability are accessing assistance with employment and 38.9% of those with multiple impairments.

Just over a quarter have a befriender (27.7%). Most of those accessing a befriender have mental health needs (65.6%) with much lower numbers reported for those with intellectual disability or ASD (n=1). There are two main reasons reported to explain the high number of young people not accessing a befriender: the service is not required or the young person does not want a befriender.

Overall, 82.8% accessed support from a personal adviser (PA). The main reasons given for no access to a PA are refusal to engage or service not required, followed by being on a waiting list for the service or ageing out of the service. However, there is a statistically significant relationship between access to PA support and impairment type with a small effect size  $\chi^2 (4, N = 314) = 10.386, p < 0.05, \phi_c = 0.18$ . Over a fifth of those with intellectual disability (22.7%) and over a quarter of those with ASD (28.9%) are not accessing PA support, compared to only 11.7% of those in the mental health category. Most of those who do have a PA have contact with them on a monthly (33%) or fortnightly (18.3%) basis, however, 19.9% do not have contact with their PA. The main reasons for no contact are: PA not required, refusal to engage or case not yet allocated/newly allocated.

## SUMMARY

- Just over two thirds of young people are in receipt of 16+ social work services, with most having contact with their named social worker on a monthly or fortnightly basis.
- 82.8% accessed support from a PA with most having monthly or fortnightly contact, however, a fifth do not have contact with their PA.
- Those with mental health needs are most likely to have access to 16+ services. Levels of access to 16+ services are reported to be much lower for those with ASD or intellectual disability.
- There is a reduction in access to 16+ social work services as care leavers aged with half of those accessing these services aged 16-17 years (50.2%), and 40.3% aged 18-19.
- Low levels of access to a befriender are reported.



### 3.7 SUPPORT FROM MENTAL HEALTH OR DISABILITY SERVICES

CAMHS provides specialist care for young people with mental health needs aged up to 18. Specialist Therapeutic Support Services (TSS) are also available for young people in care up to the age of 18. AMHS are provided to adults (18+) who have symptoms of a severe and enduring mental illness or for whom there are concerns about risk or impaired social functioning linked to mental health needs.

A fifth (20.7%) of the study sample are accessing AMHS with 15.3% accessing CAMHS, 7.6% still using LAC Specialist Therapeutic Services (for example, counselling, support with behaviour/anxiety or life story work) and 12.4% accessing early intervention services (including those provided by voluntary/community services). As expected, the majority of young people accessing these mental health services are in the mental health category (22.2% of those with mental health needs are accessing CAMHS and 27.2% accessing AMHS). However, almost half (47.1%) of those with an assessed mental illness are not receiving child or adult mental health services.

Equal proportions of males and females (50% each) are accessing CAMHS, however, females outnumber males in all other mental health services (58.3% in LAC Specialist Therapeutic services; 60% in AMHS and 53.8% in early intervention services).

Despite high levels of co-existing mental health and intellectual disability/ASD, very low levels of engagement in mental health services are reported for those with an intellectual disability (n=3 in CAMHS; n=8 AMHS) or ASD (n=2 in CAMHS; n=4 AMHS). Interestingly, however, these figures increase for those with ASD in relation to access to early intervention services with 30.8% of those receiving these services in the ASD category (46.2% in the mental health category).

A very small proportion of the study sample are accessing children's disability services (5.1%). Of those who are, most are male (68.8%) and under 18 years (87.5%). Most of those accessing children's disability services have ASD (37.5%) intellectual disability (25%) or multiple impairments (25%), although numbers are small. In terms of access to adult disability services, the numbers remain relatively small (13.1%), with 68.2% aged 18 or over and 26.8% aged 17; and a more even gender balance (51.2% male; 48.8% female). The majority of those accessing adult disability services have an intellectual disability (70.7%), followed by multiple impairments (17.1%), although numbers are small. Only two young people with ASD (co-existing with intellectual disability) are accessing adult disability services.

Across disability and mental health services, the most common reasons for the service ending were that the young person disengaged or aged-out of the service or the service aim had been achieved.

#### SUMMARY

- Low levels of engagement in mental health and disability services are reported. Only one fifth are accessing AMHS, with fewer accessing CAMHS. In addition, just over half of those with an assessed mental illness are in receipt of child or adult mental health services.
- Despite levels of co-existing mental health and impairment, very low levels of engagement in mental health services are reported for those with an intellectual disability or ASD.
- Equal proportions of males and females (50% each) are accessing CAMHS, however, females outnumber males in all other mental health services.
- Smaller numbers are reported to have access to child or adult disability services. The number of young people with intellectual disability accessing disability services increased significantly from child to adult disability services (4 in children's and 29 in adult disability services), the reverse was the case for those with ASD (6 in children's and 2 in adult disability services).

### **3.8 ACCESS TO OTHER SUPPORT SERVICES**

Social workers reported a range of other support services that young people accessed as they left care. These included short breaks, summer or leisure opportunities and input from a range of professionals and organisations.

#### **Short breaks**

Almost one in ten (9.9%) young people use short breaks, most commonly short break placements in a non-relative foster care (35.5%), specialist foster care (12.9%) or specialist residential care (12.9%). There is considerable variation in the length and number of short break stays with some young people accessing block usage (for example, weekly blocks in residential settings during the summer) and others only spending parts of the day/evening in short breaks (no overnights).

Almost a third of young people accessing short breaks are in the NHSCT (32.3%), followed by a quarter in the WHSCT (25.8%). A much lower number of young people are accessing short breaks in the SEHSCT (6.5%). This variance in numbers accessing short break may reflect different levels of availability of short break services across the region.

The majority of short break users are in the mental health category (48.4%), followed by multiple impairments (25.8%) and intellectual disability (16.1%). The majority are aged 16-17 years (74.1%) with a quarter aged 18+ years. Of those young people using short breaks, more than half (51.6%) use short breaks as a planned break for a parent or caregiver or to support a current care placement and an additional 12.9% have experienced unplanned short break placement in response to a crisis. It is notable that only 38.7% use short breaks as a social opportunity for the young person.

#### **Summer or leisure opportunities**

Relatively small numbers of young people in the study sample are recorded to access summer or leisure opportunities. Only 1.9% are accessing Special Olympics activities, with a further 7% accessing specialist summer/leisure opportunities and 5.1% accessing holiday provision.

Slightly higher numbers of young people are reported to access summer schemes (11.5%) which could be available as part of the package of support from 16+ services or from their specialist school or placement provider. In addition, 11.8% access other social activities. Some of these young people are independently participating of social activities, such as, a local gym, football team, choir or band.

#### **Direct payments**

Only 4.5% (n=14) are reported to use direct payments, mostly living in the BHSCT (35.7%), NHSCT (35.7%) or SHSCT (14.3%). This finding indicates a low uptake of direct payments for care leavers and a possible area for further service development, including raising awareness of the possible use of direct payments among 16+ social work teams and care leavers themselves.

### **Other statutory and voluntary/community sector services**

Almost one fifth (19.1%) of the survey sample are accessing transition support from the education sector, mostly young people are aged 16-18 years. Services from the education sector include transition planning, careers officer support, work placements and transitional college classes.

Overall, 43% are using other statutory or voluntary/community services including disability related organisations (for example, Mencap, Praxis Care, Triangle, Autism Initiatives, Action Mental Health, Cedar Foundation) and care leaver/youth related organisations (for example, VOYPIC, Action for Children, Include Youth, Extern, MACS, Belfast Central Mission, Prince's Trust, Barnardo's, Simon Community and NIACRO). Types of services include floating support/accommodation support, programmes related to personal development, social opportunities, mentoring, counselling, drug/alcohol treatment and diversionary activities. Other statutory services include employability or university/college support.

The majority (67.4%) of care leavers accessing these other services are in the mental health category and aged 16-18 years.

### **Other professional support**

A wide range of other professionals are also involved in the lives of care leavers including, dentistry, GP, psychiatry, psychology and solicitor. Low levels of access to nursing care are reported (4.8% inpatient nursing and 5.1% community psychiatric nursing). In addition, it is concerning that only 8.9% are reported to have access to a mentor and 5.7% an independent advocate. In addition, a concerning low number of young people are accessing a transition coordinator (n=9). The very low numbers of disabled care leavers accessing these professionals is concerning, particularly those related to transition to adult life and ongoing disability related needs.

#### **SUMMARY**

- Almost one in ten young people use short breaks, most commonly in a non-relative foster care setting with varying length and number of short break stays. There are no major differences in the gender of short break users however, most are aged 16-17 years and in the mental health category. For more than half of those availing of short breaks, the service is provided as a planned break for a parent/carer or to support a current care placement. Only just over a third report short breaks to be a social opportunity for the young person.
- Small numbers of young people are reported to access summer or leisure opportunities.
- Low levels of uptake of direct payments are reported indicating a need to raise awareness of the possible use of direct payments among care leavers and staff in 16+ teams.
- Almost one fifth of the young people are accessing transition support from the education sector and almost half are using other statutory or voluntary/community services including disability and care leaver/youth related organisations. The majority of care leavers accessing these services are in the mental health category and aged 16-18 years, indicating that these services are often targeted at younger care leavers or that older care leavers disengage from services.
- A range of other professionals are also supporting care leavers, however, it is concerning that very low levels of support from mentors, independent advocates and transition coordinators are reported.

### 3.9 SAFEGUARDING AND RISK-TAKING BEHAVIOURS

More than one in five (21.3%) of the study sample have attempted suicide in the preceding 12 months, with similar proportions of females (22.7%) and males (20.1%). Of those who have attempted suicide, 43.4% have attempted suicide more than once and more than a fifth (22.4%) are aged 16 (at the time of the survey). Just over one quarter (28.4%) of these young people are in receipt of CAMHS and almost one third (32.8%) are receiving AMHS, with 9% receiving LAC specialist therapeutic services.

In terms of risk taking behaviours, 28.3% of young people are reported to be at high to medium risk of engaging in risky sexual behaviour. More than two fifths (22.6%) of young people are reported to be at high to medium risk of suicide, and 36.9% are at high to medium risk of substance abuse. Almost equal numbers in the high (14%) and medium (14.3%) levels of risky sexual behaviours; whilst more young people at medium (14.6%) than high (8%) levels of suicide. In contrast, many more young people are at high level of risk of substance misuse (22.6% compared with 14.3% at medium risk level).

Three quarters (75%) of young people in the high risk sexual behaviour category are receiving services and a further 18.2% have been referred to services. Similarly, 80% of those with a high risk of suicide are receiving services and a further 16% referred to services. However, of those at high risk of substance misuse, less than two thirds (60.6%) are in receipt of services and more than a quarter (28.2%) have been referred to services.

At the high level of risk, there are slightly more females in the categories of risky sexual behaviour category and risk of suicide (52% in both), however, more males (67.6%) at high risk of substance misuse. Overall, males are two times more likely than females to be at high risk of substance abuse ( $\chi^2(1, N = 314) = 7.916, p = 0.005, \phi = -0.167, OR = 2.28$ ).

Those with intellectual disabilities are reported to be at the highest level of risky sexual behaviour (34.8% of young people with intellectual disability) and lowest risk of suicide (9.1%), with just over one fifth at high/medium risk of substance misuse (21.2%). In contrast, high levels of risk of suicide (32.8%) and substance misuse (51.7%) are reported for those in the mental health category, with just over one quarter (26.3%) reported at high/medium level of risky sexual behaviour. Lowest levels of risks across categories are reported for those with ASD with the exception of risky sexual behaviour where over a quarter of those with ASD (26.3%) are reported to be at high/medium level of risk.

#### Cautions and Convictions

A considerable number of young people have received a police caution (40.8%), with some having multiple cautions. In relation to gender, 45.1% of males have received a caution in comparison to just over a third (36%) of females although the association between gender and receiving a caution was not statistically significant. The majority of young people (66.1%) have been cautioned after coming into care, although almost a quarter (23.6%) received cautions both before and after becoming LAC.

Almost a third (30.6%) of the study sample have received a conviction. Of those who have been convicted, 37.8% are male and 22.7% are female. Moreover, males are two times more likely to have received a conviction than women ( $OR = 2.07$ ) and the association between gender and convictions is statistically significant ( $\chi^2(1, N = 314) = 7.760, p < 0.01, \phi = 0.16$ ). The majority of young people have been convicted after coming into care (72%), although a significant proportion of young people receive convictions both before and after becoming LAC (20.4%).

Those with mental health needs, followed by those with an intellectual disability are most likely to have cautions and convictions: half of those with mental health needs have been cautioned and 41.7% convicted; whilst almost one third of those with an intellectual disability (30.3%) have been cautioned and just over one fifth convicted (21.2%). Whilst similar numbers of those with ASD have been cautioned (28.9%), in contrast, only 13.2% had been convicted. Overall, young people who have received a conviction are 3.8 times more likely to have mental health needs than those who had not received a conviction.

For 21 young people, social workers provided information on the outcome of the conviction. The majority received a Youth Conference Order (38.1%), however, almost a fifth (19%) received a custodial sentence.

#### **SUMMARY**

- More than one in five of the study sample have attempted suicide in the previous year with no major differences in gender. Of these, 43.4% have attempted suicide more than once and more than a fifth are aged 16. Just over one quarter of these young people are in receipt of CAMHS and almost one third receiving AMHS.
- High levels of risk are reported in relation to substance misuse, however, more than a third of these young people are not receiving services to address these risks. In contrast, three quarters of young people at risk of exploitative or other high risk sexual behaviours are receiving services.
- There are slightly more females in the high levels of risky sexual behaviour category and suicide, however, more males are at high risk of substance misuse.
- Young people with intellectual disability or ASD are at higher levels of risky sexual behaviour. In contrast, higher levels of risk of suicide and substance misuse are reported for those in the mental health category.
- A considerable number of young people have received a police caution (40.8%), mostly after they came into care and some with multiple cautions. More males than females have been cautioned.
- Almost a third of the study sample have received a conviction, mostly after coming into care, and almost two thirds of these are male.
- There are higher rates of cautions and convictions for those with mental health needs, followed by those with an intellectual disability. Whilst similar numbers of those with ASD have been cautioned, in contrast, only 13.2% had been convicted.
- The majority of those convicted received a Youth Conference Order, however, almost a fifth received a custodial sentence.

### **3.10 CARE LEAVER INCOME**

Over a third of young people (33.8%) are in receipt of Disability Living Allowance, a quarter (25.2%) in receipt of housing benefit, a fifth are receiving Employment and Support Allowance (20.4%) and 18.8% are receiving Jobseeker's Allowance. However, more than a fifth of the study sample (23.9%), are not in receipt of any benefits. Of those not receiving benefits, 17.3% are Not in Education, Employment or Training (NEET); 12% are at a training centre, 6.7% are pre-vocational, 14.7% are in paid employment, and 5.3% are at university and 17.3% are in mainstream education. Almost two thirds of those not in

receipt of any benefits are male (61.3%) and in the mental health category (65.3%), and almost three quarters (73.3%) are aged 16-17 years.

Social workers completing surveys were asked to provide an approximate estimate of each young person's current weekly income. This data was missing for almost one fifth (20.4%) of the sample. From the data provided, the majority (44.4%) are living on £51-100 per week, followed by £1-£50 per week (17.1%). Just over one quarter (27%) receive over £100 per week and only 15.7% receive over £150 per week.

#### **SUMMARY**

- Almost one quarter of young people are not in receipt of any benefits and, of these, 17.3% are Not in Education, Employment or Training (NEET).
- Almost two thirds of those not in receipt of any benefits are male and in the mental health category and almost three quarters are aged 16-17 years.
- From the data available on income, the majority of care leavers (61.5%) are living on less than £100 per week, indicating vulnerability to the range of risks associated with poverty.

### **3.11 EDUCATION, EMPLOYMENT AND TRAINING**

Only 10.5% of the study sample are engaged in employment, similar to the 8% of those in the general care leaver population in the DSF return. However, only half of those in the survey population engaged in employment (5.7%) are in paid employment (3.2% are in supported employment and 1.6% are volunteering). Of those in paid employment, 55.6% are in permanent or temporary full-time work with a smaller proportion employed on a casual (5.6%), part-time temporary (22.2%) or part-time permanent (16.7%) basis. Two thirds of those in paid employment are male and half of those in paid employment are aged 18-19 years. The majority of those in paid employment are in the mental health category (61.1%), followed by equal proportions of those with an intellectual disability or ASD (16.7% in both categories).

Overall, 34.1% of the survey sample have a statement of special educational needs and 19% are still in school (mainstream or specialist). A further 12.7% are attending a training centre and 11.5% are attending further education colleges (lower than 19.5% for the general population attending further education colleges reported in the DSF return). Only 1.6% are studying at University, compared to 4.9% for the general population in the DSF return. A further 8.4% are considered to be pre-vocational with some of these young people attending employability programmes and courses offered by Give and Take or Connections programmes. This is similar to the figure (9.2%) for the general population in the DSF return.

Whilst most of the study sample experienced no or few school changes, (43.9% had none; 42% had 1-2 school changes), more than one in ten (11.8%) had between three and nine school changes, most likely reflecting placement change reported earlier in the report. This level of school change is likely to have a significant impact on their educational experience and performance. The majority of these young people have mental health needs (62.2%), with 18.9% having an intellectual disability.

Almost a third (32.8%) of the survey sample are not in education, training or employment (NEET). This is a higher figure than that for the general care leaver population in the DSF return (21%). Social

workers indicated that the main reason for NEET was the young person's disengagement, followed by pregnancy or parent/carer roles, sickness, or being in prison/out on bail.

Almost a third of those NEET are aged 18 (30.9%), followed by 22.7 % aged 17 and 22.7% aged 20. There are no major differences in gender for those in the NEET group, however, over two thirds (68%) are in the mental health category, with 17.5% having an intellectual disability and 10.3% ASD.

Most young people are receiving assistance with education and training (88.2%) or employment (66.9%). Those who are not availing of such assistance are mainly reported to be refusing to engage or not requiring assistance for a range of reasons (e.g. already in education, training or employment or living in custody/detained). However, there are notable trends in assistance with education or employment across impairment type. Compared with levels of assistance provided for education/training, there is a marked reduction in support for employment for those with an intellectual disability (from 84.8% to 57.6%). This reduction may indicate that young people with an intellectual disability are least likely to engage in employment but could also indicate lower employment expectations for these young people.

#### **SUMMARY**

- Just over one third of the survey sample have a statement of special educational needs.
- More than one in ten (11.8%) experienced multiple school changes, mostly those with mental health needs, which is likely to have a significant impact on their educational experience and performance.
- Only one in ten of the study sample are engaged in employment and only half of these are in paid employment. Of those in paid employment, the majority are male and in the mental health category. Almost one fifth of the sample are still in school.
- Almost a third are not in education, training or employment (NEET) and for almost half of these cases social workers reported that the young person does not want to engage. There are no major differences in gender for those in the NEET group, however, over two thirds are in the mental health category.
- The majority of young people are receiving assistance with education and training or employment. However, there is a drop in assistance with employment for those with an intellectual disability, reflecting lower employment expectations for these young people.

### **3.12 CONCLUSION**

For the first time, this survey has captured the characteristics of the population of care leavers with mental health and/or intellectual disabilities in NI. Based on the findings reported, it is possible to identify key trends and areas requiring service improvement to address unmet need or poorer outcomes for care leavers with mental health and/or intellectual disabilities.

1. **Co-existing impairments.** As Departmental statistical reports on care leavers do not identify co-existing impairments, it is important to note that almost one fifth of the survey sample have more than one impairment type and may need access to a range of both disability and/or mental health services.
2. **Reasons for being in care and vulnerability to abuse, neglect or family breakdown.** Variant reasons for being admitted to care are notable across the two main impairment categories: mental health and intellectual disability. Young people with intellectual disabilities are more likely than those with mental health needs to have been taken into care because of neglect,

emotional abuse or sexual abuse (although numbers are small in the latter category). In contrast, those with mental health needs are three times more likely than young people with intellectual disabilities to come into care because they are beyond parental control. These findings provide insight into potential risks of abuse, neglect and family breakdown for care leavers with different types of impairments that professionals should be aware of to enable appropriate interventions to protect these children and support their families.

3. **Placement and school disruption whilst in care.** The survey found high levels of school and placement disruption, particularly for young people with mental health needs, which negatively impacts on education and opportunities for permanence.
4. **Parenting status.** The numbers of disabled care leavers in the study sample who are parents reflect those for the wider leaving care population. The majority are female and many are under 18 and not living with their children. These findings highlight the importance of including disabled young people in educational programmes on safe personal relationships and parenting.
5. **Living arrangements.** In comparison with trends in the wider care leaver population, the survey found that disabled care leavers are less likely to have the opportunity to stay with former foster carers under the GEM scheme. There is a trend towards those with mental health needs moving on to tenancy arrangements without housing support with increased risks of poorer outcomes for those living in tenancy without support. In contrast, care leavers with intellectual disabilities are more likely to return home, which may reflect the lack of suitable supported housing or adult residential placements for these young people and may present further risks.
6. **Access to 16+ social work and personal adviser (PA) services.** 16+ services are most likely to be accessed by care leavers with mental health needs than those with other impairment types. Service planners should ensure care leavers with intellectual disabilities and ASD have equal access to the full range of leaving care services they are entitled to. Most of those who have a PA have regular contact with them, however, a fifth have no contact with their PA which is concerning if PAs are identified as the main 16+ support for young people.
7. **Reduced access to employment assistance.** Whilst almost three quarters of those with mental health needs access assistance with employment, over a third of those with ASD and 42.4% of those with an intellectual disability do not, indicating a reliance on schools or other disability-related organisations to provide this support or reflecting lower employment expectations for those with ASD or intellectual disabilities. It is essential that these care leavers have access to services targeted at assisting them to secure employment.
8. **Low levels of access to disability or mental health services.** Despite high levels of co-existing impairment, very low levels of engagement in CAMHS and AMHS are reported for those with intellectual disabilities or ASD. Similarly, numbers remain relatively small in relation to access to child or adult disability services, particularly for those with ASD. It is unsurprising, then, that low levels of contact with professionals linked to disability services, such as, transition coordinators and professionals allied to medical services. These findings indicate a need to review eligibility criteria for access to child/adult disability and mental health services to ensure access to specialist support for disabled care leavers.
9. **Access to a befriender or advocate.** Almost three quarters of the survey sample do not have access to a befriender and the majority who do, are in the mental health category. In addition, it is concerning that less than one in ten are reported to have access to a mentor and only 5.7% have an independent advocate. These very low levels of access to befriending and advocacy services indicate a need to for advocacy and mentoring service providers to target provision for disabled care leavers.



10. **Variation in short break usage.** Less than one in ten use short breaks, with particularly low levels of short break usage for older care leavers and in some Trust areas indicating a need to review the availability of adult short break placements across NI and develop the extent of these services regionally.
11. **Low levels of uptake of direct payments.** The low levels of direct payment usage suggests a need to raise awareness amongst care leavers and 16+ teams of the opportunity to access direct payments. Increased use of direct payments may provide an opportunity for more creative and personally meaningful ways to increase the low levels of social activity reported for the study sample.
12. **Risky behaviours.** Professionals should develop their awareness of the increased level of risky sexual behaviours for those with ASD and intellectual disabilities, and educational programmes should be provided for these young people aimed at raising awareness of personal safety and positive personal relationships. Whilst many of those at higher risk of suicide are receiving services, those with substance misuse problems are more disengaged from services. An audit of services for care leavers with substance misuse problems would help to inform service development for care leavers engaged in substance misuse.
13. **Low income levels and financial hardship.** From the data available, many care leavers are at risk of financial hardship at a time when they are only learning how to manage their finances. There is a need to enhance knowledge of welfare benefit usage amongst care leavers with mental health and/or intellectual disabilities and how best to support these care leavers economically as they transition from care.
14. **Withdrawal of leaving care services.** Leaving care services are targeted at younger care leavers and cease as young people age out of children's services. There is a need to examine the types of extended support required from either leaving care service or specialist adult services for care leavers with mental health and/or intellectual disabilities.

In conclusion, the survey findings provide a profile of the population of care leavers with mental health and/or intellectual disabilities in NI and indicate clear areas that require targeted policy and practice developments. As this is the first survey of its kind to capture a regional perspective on the profile of care leavers with mental health and/or intellectual disabilities, there is a need for further research to develop understanding of the needs and experiences of this population of care leavers. The final qualitative phase of this study seeks to address some of these issues further through case file review and qualitative interviews with care leavers, parents/carers and social workers. The findings of the case study phase of the research are reported in the next section of the report.

## **4.0 CASE STUDY FINDINGS**

The focus of the case study phase of the research was to explore the views and experiences of 31 care leavers and the perspectives of key professionals or carers in their lives. Care leavers described their experiences of mental health and disability and the impact of impairment on their care experience and daily lives. Interviews with young people then focused on their care pathways, revisiting their entry into care, care placement experience and contact with their birth family. As young people prepared to leave care, they engaged in pathway planning and exploration of accommodation options and experiences of supported or independent living. Young people also discussed a range of issues they faced in their transition from care to young adult life including: financial hardship; limited personal and positive social networks; new parenting roles; efforts to engage in education, training or employment; and ongoing vulnerability to exploitation or abuse.

As young people moved on from care they re-negotiated their changing identities and engaged with new service systems. Many encountered the impact of stigma in relation to care identity, disability and mental health which impacted on their self-esteem, confidence and opportunities in young adult life. However, most care leavers were keen to chart new directions for their post-care adult lives emphasising the importance of participation in decisions affecting their lives and their hopes and ambitions for their future.

This section of the report will summarise the findings in relation to each of these key topics relevant to the lives of care leavers interviewed, providing examples from case studies and extracts from some of the interviews with care leavers, carers and professionals using anonymised quotes and pseudonyms. Please refer to the full report on the case study phase of the study for more detailed discussion and analysis of the case study findings (Kelly et al, 2016b).

### **4.1 EXPERIENCE OF MENTAL HEALTH AND DISABILITY**

A total of 19 case study participants were in a sole impairment category: five with an intellectual disability, two with ASD and 12 with mental health needs. The remaining 12 participants had co-existing impairments: five had co-existing intellectual disability and ASD, four had co-existing mental health and intellectual disability and three had co-existing mental health and ASD. Young people shared their experiences of how mental health and disability impacted on their daily life and their care pathways.

#### **4.1.1 Mental Health**

Young people in the mental health category had been diagnosed with illnesses (such as depression, anxiety disorders, PTSD or eating disorders) and experienced fluctuations in their mental health. At the time of the study, some care leavers were attending appointments with mental health professionals or relying on medication prescribed by their GPs without specialised treatment from mental health services. Others were struggling without any form of professional support regarding their mental health.

For many, mental ill health impacted on a range of aspects of their lives, such as, friendships and employment opportunities. Others had found strategies for managing their mental illness, such as, self-care activities, keeping busy or seeking support from former carers. For some young people a clear

diagnosis of a mental health condition was important in terms of understanding symptoms and how to manage their condition:

*It was good... that they put a finger on it... That kind of helped me when I was freaking out... Then they started telling me what the condition was, what it involved, what the traits of it were. So you kind of knew how to manage it... Knowing about it and having the knowledge is a good thing (Louise).*

Some care leavers also indicated that their mental ill health linked to the inter-generational experience of ill mental health in their family and the impact of their previous experiences of neglect/abuse and out-of-home care.

Other young people were unsure about their mental illness and the purpose or effects of medication. Some young people were not taking the dosage of medication as prescribed or had stopped taking medication for periods of time. In addition, several care leavers were not happy to have a diagnosed mental illness and disputed their diagnosis, often due to a lack of information/understanding about their mental illness and/or an awareness of stigma associated with mental illness:

*I don't want to have bipolar cos you can't get rid of it... I more than likely do have it. But I just don't really want to tell myself I do (Sara).*

For some care leavers, there was an improvement in their mental health during the course of the study as they moved on from care. However, others were not managing so well and described struggling with mental illness and the challenges of leaving care on a daily basis. In some of these cases, young people had disengaged from mental health services and also ceased involvement with 16+ teams.

Carers who kept in regular contact with young people who had left their care were able to recognise a deterioration in their mental health, often in the early stages, and offered intensive support to care leavers at these times. Social workers also noted how positive informal support networks could help to prevent a breakdown in mental health, including support from birth family members and former carers. However, most care leavers had very limited support networks and felt disconnected from their local communities.

#### **4.1.2 Suicide, Self-harm and Substance Misuse**

In total, 11 case study participants had attempted suicide. For many of these young people, suicide attempts were linked to a personal crisis (e.g. a breakdown in a personal relationship), difficult family dynamics and/or substance misuse. For several, bullying was also an instigating factor in their suicide attempts.

Some young people were supported by specialist mental health services to recover from suicide attempts, including hospital care and community-based services. Indeed, in some cases, a severe mental health crisis or period of hospitalisation had been a turning point in the lives of care leavers who then began a journey of recovery. Social workers spoke of the stress of managing high level risks of suicide for young people on their caseloads. They also struggled to cope with the aftermath of death by suicide in relation to young people who had been on their caseloads.

*Suicide is a big risk for us to manage... We run with very high risks in the 16+ world and we risk manage frequently a lot of our young people... it does impact on you (Laura's social worker).*

Most young people in the sample had self-harmed with varying degrees of severity, with some still engaged in self-injury during the study, although these behaviours seemed to have reduced in terms of severity and regularity:

*Self-harming was a coping mechanism for me. It was an easy way to get all the s\*\*t out without losing my temper. So it became my way of living... I would love to just cut and get it all away but... Not much point. No more. Sick of having scars from head to toe (Imogen).*

Other study participants self-harmed through substance misuse including a range of legal and illegal drugs and alcohol. Exposure to drug taking behaviour was more prevalent among those leaving residential care. For some, use of alcohol or other drugs was a way of self-medicating, for example, one young person engaged in regular cannabis use to stabilise her emotional state.

Birth families could play a part in care leavers' misuse of substances by either providing or encouraging risky behaviours. In other cases, birth family members had a positive influence, motivating young people to cease substance misuse. For example, kinship carer threats to withdraw support encouraged some young people to stop drug taking behaviour.

For some young people, social workers were worried that substance misuse linked to engagement with a negative peer network which also led to additional risks of sexual exploitation and criminal activity.

#### **4.1.3 Experience of Impairment and Disability**

Young people in the intellectual disability and ASD categories were described as having a range of borderline to severe levels of impairment. Some young people recalled a sense of relief associated with being given an official diagnosis of a disability as it helped them to understand impairment effects, particularly those who had waited some time for a diagnosis and had delayed access to disability services. For young people with severe and multiple impairments, impairment affected many aspects of their lives. Other young people with less severe levels of impairment gave examples of how additional learning support or alternative communication strategies helped to reduce the disabling effects of impairment. Some young people with ASD acknowledged a preference for isolation from peers and public spaces and made deliberate efforts to engage in more social activities to widen their access to informal support.

Some social workers who adapted their approach to working with young people with various impairments described offering young people more control over decisions, use of repetition techniques as reminders for medical appointments and an emphasis on building a trust-based relationship with disabled young people.

Whilst some disabled care leavers could clearly articulate their impairment experience, others were struggling with impairment labels that had been ascribed to them. For example, whilst Imogen appreciated that her recent diagnosis helped her to understand her behaviour and difficulties in group settings, she found it difficult to accept and felt that others held low expectations of her abilities:

*When I was diagnosed it was always everything bad... It was like 'you can't do this, you can't do that'. 'You'll not understand this, you'll not understand that'... 'You won't understand jokes unless they're very very simple'... 'You won't understand people's facial expressions'... There was never a positive (Imogen).*

Many disabled young people had a desire to feel the same as non-disabled people in society and were keen to achieve independence and make self-determined choices about their post-care lives.

Furthermore, several young people described 'hiding' their disability from peers and partners. Others did not accept their diagnosis as they experienced little or no impairment effects or had received very little information about their condition. For example, Jack did not feel he was disabled:

*I don't usually put it [Asperger's] down on the paperwork... it doesn't really affect me... If you say you have Asperger's they automatically assume you need support... I don't want support (Jack).*

In addition to impairment experiences, some care leavers experienced disabling barriers in society including low expectations that they would secure work placements or employment. Others encountered social exclusion or bullying because of their impairment. That impacted on how care leavers understood their impairment and, for some, denial of their impairment was a strategy to keep themselves safe in the context of multiple experiences of disablist bullying:

*I have a mixture of both ADHD and autism... I was trying to keep it a bit of a secret... Everybody knew then that became the brand new reason to bully me (Danny).*

#### **4.1.4 Care Leavers with Borderline Impairments**

There was great concern among social workers and carers for young people with borderline impairments who did not meet the criteria for disability or mental health services. Although these young people did not have a clear diagnosis, they had ongoing unmet needs and were forced to rely on 16+ services to meet the full range of their needs. As a result, young people with borderline impairments often struggled to secure appropriate post-care accommodation:

*Sometimes unfortunately it's like if they don't have a label, you can't get the services... They'll say they're borderline... It's awful. It happens so many times (Jamie's social worker).*

Whilst 16+ services often did their best to meet the needs of these young people, their staff did not have specialist knowledge of disability or mental health and could not secure their access to specialist services. It was also challenging when young people with borderline impairments did not perceive themselves to be vulnerable and made decisions about their lives and leaving care that was deemed to put them at further risk.

## SUMMARY

- Some young people had diagnosed mental illnesses and were in contact with specialist mental health services, however, several were not receiving specialist support despite ongoing mental health needs, including ongoing self-harm and suicidality.
- Several young people who had previously lived in foster care placements continued to avail of informal support from former carers in relation to their mental ill health.
- Some care leavers with an intellectual disability or ASD were reluctant to engage with disability services, particularly if they were diagnosed in their late teens, often due to perceptions of stigma or paternalistic service approaches.
- Social workers in 16+ services used a range of strategies to engage with young people who were sometimes unwilling to be referred to adult disability or mental health services. Partnership-based approaches focused on young people's capabilities were key aspects of effective practice.
- Social workers in 16+ teams were concerned about managing high level risks for young people with mental illness with limited access to specialist services, particularly for those who had specialist support needs but could not gain entry to adult services.
- There was also concern among social workers and carers for young people with borderline impairments who did not meet the criteria for disability or mental health services and were forced to rely on 16+ services to meet the full range of their needs.

## 4.2 CARE PATHWAYS

Care leavers' earlier experiences of coming into care and living in various care settings set the context for their experience of leaving care. Young people involved in the case studies had a range of pre-care and in-care experiences. Some moved into family-based settings with kinship carers or non-relative foster carers and others into mainstream children's residential homes. In addition, some young people with more severe impairments had experience of secure care, specialist residential care or hospital care.

### 4.2.1 Pre-care Experiences

Age of first entry into care in the case study sample ranged from birth to 17 years. Some young people who had come into care at a young age had difficulty remembering the reasons why they came into care. Others had been old enough to remember the day they came into care and often had clear memories of this event. Young people described feeling 'scared', 'worried' and 'upset' when they were first taken into care:

*When I first went in to residential care it was completely difficult... The social worker had clothes in her hand, not even a bag and literally you are walking down a long corridor, and it is like you are going to your jail cell (Imogen).*

Despite having suffered neglect or abuse at home, many recalled desperately missing their parents and, in some cases, siblings. Those who were placed with siblings remembered a sense of relief and comfort at being able to remain with at least one sibling.

Young people's recollections of neglect, abuse, abandonment or growing up in the context of domestic violence or parental substance misuse highlighted prior negative experiences of parenting which

continued to impact on their lives as they left care and their ongoing relationships with their birth parents:

*All I can really remember is my mum being in bed most of the time and we would have to ... at three or four, try to... make something to eat if we were hungry... The stuff that your mum should be able to do for you (Jamie).*

Despite recalling memories of abuse and neglect, some young people offered insight and a degree of sensitivity regarding their experience of compromised parenting. In some cases, young people felt that their parents' own experiences of childhood neglect or abuse contributed to their struggles to successfully parent themselves. Many young people also acknowledged that parental mental health, disability and substance misuse impacted on their parents' ability to provide adequate care for them.

Some participants also remembered being increasingly beyond parental control, recalling violent rows with parents and other family members, sometimes involving police and contributing to their admission into care. Other crisis situations initiating social services involvement with young people were episodes of self-harm or suicide attempt.

In the case study sample, young people with severe intellectual disabilities and challenging and violent behaviours were primarily taken into care due to being beyond parental control and posing a risk to other family members in the home.

Social workers highlighted the lasting effects of abuse or neglect on young people. For example, some care leavers attributed their mental ill health or substance misuse issues to their earlier pre-care experiences or their separation from birth family.

Informal support from extended family members and friends, however, could be significant sources of practical and emotional support for children and young people before their full-time entry to care and, for some in kinship care, continued to play a key role in their lives during and after care. Most young people had varying degrees of support from extended family members, particularly aunts, uncles or grandparents.

#### **4.2.2 Kinship and Non-relative Foster Care**

Nine young people in the sample had experienced kinship foster care mostly with aunts, uncles and grandparents. Some young people stayed with extended family members on a short-term basis to offer a break or time for parental recovery before returning home. In some cases, young people were placed with relatives whose caring capacity was compromised by substance misuse or other needs. However, two young people remained in long-term kinship care and described positive experiences of these placements and strong relationships with their carers:

*They're my parents... They've just been there all the years and I adore them... (Lorna).*

Social workers were also positive about kinship foster care placements and the connections it offered to wider birth family relationships.

More than two thirds of the case study sample (n=22) had experienced one or more non-relative foster placements during their time in care with mixed experiences reported. Some young people had settled in long-term placements and were fully integrated into their foster families and their extended family networks. At the time of the study, two were living in their placements under the GEM Scheme and were expected to stay with these foster families indefinitely. In many cases, foster carers cared deeply

about the young person in their care and made much effort to provide support and accommodation for them:

*I had a fantastic relationship with them... The best foster parents definitely... I had a great life... (Sam).*

Other non-relative foster placements were not so positive and some young people remembered their time in these settings as unhappy periods in their lives:

*She wasn't really good to us. She... locked us in our rooms and all and social workers figured it out so moved us... She was horrible (Sara).*

Some young people struggled to adjust to structured boundaries in non-relative foster placements and family routines, reflecting the lack of structure in their lives before entry to care.

#### **4.2.3 Residential Care**

Overall, half (n=15) of the young people in the case study sample had one or more periods in residential settings throughout their time in care. Residential placements included mainstream children's homes, intensive support units, secure care, psychiatric units or specialist residential care or hospital care.

Teenagers with more complex needs were most likely to be placed in residential rather than family-based placements, or to experience a combination of placement types. Mainstream children's homes were the most common type of residential placement and there were mixed views of living in these settings. Some recalled feeling frightened and unsettled in a communal setting where privacy and quiet time was replaced by an environment characterised by chaos and disorder:

*It was scary... because I went from like a home life... into a sort of communal environment with maybe ten other kids... and then you have the staff as well and there was so many people about all the time and there was no time for thinking or space... There was no down time... where you just sat by yourself (Joanne).*

Others appreciated the structure of residential care, preferring congregate care to living with a family and developing close relationships with some staff members:

*That was my favourite place... I loved it up there... It was just nice, every staff member was nice. All the kids and all. [Staff] took you out every day and done whatever you wanted (Connie).*

However, residential care did not always prepare young people for the transition to adult life in terms of housekeeping and independent living skills. Social workers also indicated that young people placed in residential care had a more abrupt transition from care on their 18th birthdays than those in foster care arrangements.

Four young people in the case study sample had experience of secure settings, often moving between children's residential homes, secure care and intensive support placements. For some, the structure of more secure or intensive placements had a positive impact on their mental health and behaviour, given the strong boundaries and routines in place.

Three young people lived in specialist residential care facilities for disabled children with complex needs or challenging behaviours and, on reaching the age of 18, moved to specialist adult disability residential homes. Their parents and social workers commented on the individually tailored support



provided by the staff team in these settings. However, securing these specialist adult placements was often challenging as the availability of placements and funding was often uncertain during the transition from care causing distress and anxiety for young people and their parents.

Psychiatric placements accommodated young people who had more acute mental health needs. Overall, 12 of the young people had experience of psychiatric hospital care, often in relation to risk of suicide or eating disorders. Some young people described hospital settings as frightening or dangerous environments. However, others were positive about their experiences of both child and adult psychiatric in-patient care and the contribution that care made to their recovery. It was noted, however, by young people and social workers that there was a lack of specialist psychiatric care for young people in NI.

#### **4.2.4 Placement Stability**

Most of the young people in the case study sample experienced placement moves during their time in care. Overall, 18 young people had between 1-5 placement moves, with two experiencing 6-9 placement changes and four having more than 10 moves.

Placement instability tended to affect young people in adolescent years and upwards and, although some placement changes were unrelated to the needs of the young people (for example, carer illness), many were linked to issues such as young people's behaviour or mental ill health:

*When I was in foster placements... I was constantly being moved... shipped from home to home... I used to feel like the odd one out... and social workers... used to change all the time so I'd be waiting on different people... to get me from school to take me home... I never understood what was happening... So my only way of getting somebody's attention was to act out... I had behavioural problems... I was very hard to deal with... It was more of a matter of trying to find somebody who could cope with me being like that (Laura).*

Young people with severe mental health needs, particularly those who had co-existing intellectual disabilities, tended to move placements most often. Young people who experienced multiple placements often described feeling confused by placement changes and experienced loss of friendships and school changes as a result of placement moves. Experiencing numerous placements also had a negative and lasting effect on young people's ability to trust others and form or maintain personal relationships.

#### **4.2.5 Impact of Mental Health and Disability on Care Experiences**

A third of the young people (n=10) had been diagnosed prior to their entry to care (all but one with an intellectual disability). The remaining 21 young people were identified as having a mental health and/or intellectual disability during their time in care and only five of these young people were diagnosed on entry to care (four with a mental health condition and one with an intellectual disability).

Mental health needs and/or intellectual disabilities impacted on the young people's care experiences in three key ways. Firstly, placement type was determined by the type and level of a young person's needs. Participants who entered care as adolescents with a combination of deteriorating mental health and/or increasing aggression or behavioural issues, often had a crisis driven entry to specialist and/or secure care where they had access to intensive support and supervision by highly trained staff.

Secondly, young people's mental health and/or intellectual disability related needs could contribute to multiple placement moves. Fluctuations in mental health, challenging behaviours or risk of harm to self or others often led to placement change. Specialist foster care placements offered more stable placements for these young people as carers had specialist knowledge and skills to meet their complex needs, however, the availability of these placements was limited.

Thirdly, impairment effects could be exacerbated in some care settings where their needs are not well met, particularly for those in mainstream group care settings where disruptive group dynamics and a changing staff team could create challenges for care leavers with intellectual disabilities or ASD:

*With all this noise... Because of my ASD, I don't really like noise. Cos I can't control this I don't like it... I don't like when I have a routine and someone ruins it. They always try and change the rules in here... and I was like 'No you can't do this. You're ruining my routine. You're wrecking it'... Ever since I moved in I've hated it... The staff change... They just don't have time for you (Imogen).*

#### **4.2.6 Contact with Birth Family**

For most young people their separation from birth parents and entry to care had led to a sense of loss, fear and anxiety. Although many understood the reasons for their admission to care and most agreed it was a necessary step to ensure their safety and wellbeing, the significant impact of separation remained.

At the time of the study, only six out of the 31 participants enjoyed positive relationships with one or both birth parents. In addition, one or both parents of eight young people were deceased and a few care leavers had never met their birth fathers and/or were uncertain of their paternal identities.

Young people who had been voluntarily admitted to care because their parents could no longer cope with their challenging behaviours enjoyed regular, ongoing contact with birth parents who continued to play an important role in their lives. Some parents also had shared care arrangements whereby their son/daughter returned for overnight stays at home when their behaviours were settled.

In contrast, the majority of young people had strained relationships or no contact with one or both birth parents. Lack of parental commitment to the relationship was cited as a main reason for ongoing poor relationships with parents. Unreliability in terms of contact arrangements and being let down by parents also took its toll on relationships:

*I haven't been in contact for over a year now with them. It does hurt a bit but... I told them that was it. I gave them loads of chances. Not a very nice family (Dawn).*

Parental ill-health or disability also affected contact with birth family for many young people as parents were too unwell to make contact visits. Parental mental illness and substance misuse that had often contributed to the young people's entry to care also had an ongoing impact on the quality of contact with birth parents which impacted on care leavers' self-esteem and sense of identity.

As young people left care, some experienced more unrestricted time with birth families. However, social workers had concerns about reunification with birth parents who had a history of exploiting their son/daughter or had a negative impact on young people's emotional wellbeing. For many care leavers, limited, inconsistent or negative experiences of re-established contact with birth parents also left them feeling a renewed sense of rejection.

Social workers played an important role in terms of helping care leavers to understand the behaviour of their birth parents and to support them emotionally from the damaging effects of negative experiences of family contact. Some care leavers had come to terms with dysfunctional family relationships and the realisation that family dynamics may never improve. Indeed, some care leavers had made an active decision to withdraw from birth family due to the negative effect contact had on their mental health:

*Whilst you always want to have a good relationship... realistically it's not going to change... I've just had to... take a step back... I barely even ring her... She's a complete nightmare (David).*

Several young people also indicated that the severe impact of abuse and neglect were often not fully comprehended by extended family members who sometimes made well intentioned attempts to reconcile care leavers and previously abusive parents.

In addition, there were some cases where parents refused to continue the relationship, sometimes due to their disapproval of the young person's life style or mental ill health. In addition, when parents were reluctant to engage with social services, contact with birth parents was difficult to maintain.

### **Sibling contact**

The majority of care leavers in the case studies (n=25) described their relationships with siblings as strong or mixed. Most siblings had similar experiences of poor parenting, neglect or abuse and felt they had strong and supportive relationships based on shared trauma. Some had been placed in care with siblings or enjoyed close and regular contact with siblings during their time in care. However, siblings were often separated due to lack of suitable joint placements, complexities of care needs or child protection issues.

Other young people described more mixed or negative sibling dynamics where relationships with siblings were strained and contact was minimal, if at all:

*All my brothers and sisters have been in foster care... Our relationship is kind of awkward because we don't really know each other (Jamie).*

A breakdown in relationship with birth parents could also block sibling contact. Two care leavers were prevented from having contact with younger siblings who were living with parents due to negative relationships with their parents.

At the time of interview, many of the young people were separated from siblings geographically as siblings lived in different parts of the country or had moved abroad which restricted contact due to insufficient finances to cover travel costs.

Finally, in cases of care leavers with severe or multiple impairments who were voluntarily accommodated in specialist settings, social workers noted the impact on siblings who remained at home and missed their disabled brother or sister who was in care.

## SUMMARY

- Remembering life before care and experiences of coming into care are important memories for many care leavers. Prior negative experiences of neglect, abuse or abandonment continued to impact on the lives of care leavers and on their relationships with their birth parents.
- Care leavers often had insight into the circumstances and needs of their birth parents which were linked to their inability to provide adequate care and supervision.
- Informal supports from extended family members were significant sources of practical and emotional support for before their entry to care and during their time in care.
- Young people experienced various types of family based and residential or specialist care placements.
- Some had multiple placement changes which caused much instability in their care experience.
- Mental ill health and intellectual disability could influence the type of placement available, placement stability and contact with family.
- Most care leavers had ongoing issues related to birth family contact and some had negative or strained relationships with parents. Others had re-engaged with birth families as they moved on from care, although, some carers and social workers were concerned about the risk of exploitation of the young person.
- For care leavers who had close sibling contact they were an important source of informal support, however, others had fractured relationships with siblings due to separate placements and risk concerns.

## 4.3 LEAVING CARE

Efforts to prepare young people for leaving care involved former carers, social workers and schools. Staff in 16+ teams played a key role in pathway planning and supporting young people as they transitioned from care into their young adult lives. For those leaving CAMHS or children's disability services, there were also re-assessments and decisions to be reached about access to specialist adult services.

### 4.3.1 Pathway Planning

The majority of young people had a written pathway plan and most young people knew that decisions about their transition from care and their future were set out in these formal plans. There was a consensus among young people and social workers that care leavers had a greater say in decisions affecting their future at post 18 than when they were in care and subject to LAC procedures:

*Under 18, their statutory LAC reviews... need to take place and they don't really have as much say in who they can have there. Once they turn 18 and their pathway plan review, they do have a say. It's up to them who comes 100%... It's their decision (Jamie's social worker).*

Participation in decisions about post-care lives increased the control young people had over their lives and gave them a greater sense of empowerment as they were invested in plans for their future and working in partnership with professionals to achieve their goals. Involvement in reviews of pathway plans also gave care leavers an opportunity to report on action taken on goals identified, thereby providing a mechanism to make 16+ teams and other service providers more accountable.

Participation in pathway planning and decisions about their own lives could also build capacity for care leavers to participate at a range of other levels. For example, one young person was involved in interviews for new staff members in a 16+ team and another had made representations on care leaver issues to policy makers.

However, despite social workers' efforts, young people were not always active participants in the pathway planning process and there was often concern about the disengagement of care leavers with mental health and/or intellectual disabilities from these formal planning processes.

Young people explained that there were several reasons for their withdrawal from participation in pathway plans. Firstly, those experiencing a personal or family crisis or who were experiencing acute mental illness did not feel ready to engage in planning processes focused on their futures. Secondly, some felt that former carers and professionals dominated decisions about their future and left them with little opportunity to play an active role in the planning process:

*They need to obviously listen to the young person... I wasn't asked once in that meeting. Everybody was talking amongst. There must have been about six or seven people in that meeting... There was staff members, key workers... So there was all them and they were all making decisions about me and me sitting there listening (David).*

*Some of the things on it [PATH plan]... people are putting ideas inside. Like X [former carer] is busy saying 'Oh no that's a good idea keep that'. She put ideas of her own down... and I hated that. I hate people making decisions for me (Simon).*

Social workers described involving parents and carers in planning processes and decisions about post-care lives. Indeed, some young people relied on their parent, sibling or carer to help them to communicate their views on matters relating to their pathway plans. However, whilst social workers highlighted the benefits of parents and carers representing the best interests of young people, they also highlighted the importance of providing more independent advocacy for care leavers with mental health and/or intellectual disabilities.

In relation to professional roles in pathway planning, several young people indicated that planning processes were really a mechanism for professionals to share their views and plan for the young person's future:

*You go in and people are talking about you as if they know you and they haven't a clue... I think it's just so everybody is on the same page. Like there's stuff my PA would know that my social worker didn't know. And they would be like, 'Well you never told me that'.... Don't make it so professional all the time because that would scare somebody off... You always feel like you've done something wrong even if you haven't... If they weren't so naggy, strangers in a room. I hate that. My foster mum does all the speaking. I fill in the book myself but I don't speak at all (Chloe).*

Interestingly, however, some social workers spoke of challenges related to engaging other professionals in pathway planning processes.

Most 16+ social workers acknowledged that care leavers disengaged from planning processes if they were viewed as professionally dominated environments where the detail of their lives was subject to discussion. They emphasised that the genuine participation of care leavers required an empowering approach that recognised the rights of care leavers with mental health and/or intellectual disabilities to make their own decisions and to learn by their mistakes:

*We tried to inform her so she could make informed decisions but she made completely her own decisions every single time... all we can do is to inform... Lay out all their options... and suggest what would be really good and not so good but at the end of the day they're young adults and they will make their own decisions (Dawn's social worker).*

Thirdly, both young people and social workers expressed dissatisfaction with the pathway planning process in terms of length, repetition and use of patronising cartoon imagery:

*Pathway plans are still very childish... Make it more grown up because they seem to forget it's adults they are dealing with... Stop using cartoons that a pre-schooler would use on a document... Don't treat them like children... because I have had social workers that will speak down to me like I am a child just because I have got a mental disability. And I am sitting there and I said to them 'I am coming 20. I'm not five' (Danny).*

*I don't think the forms are user friendly for an 18 year old... They're an adult and we're expecting them to fill in a form with cartoon pictures on the front of it... A lot of young people do actually make that comment on that... Even though they may have a learning disability... they deem themselves to be 18 and quite able.... I think they're a bit repetitive as well... It needs to be structured in a different way... It is quite lengthy for any young person, especially maybe with mental health needs, when you're trying to fill that in with them and get their participation, their concentration does go (Norah's social worker).*

Participants with moderate to severe intellectual disabilities and/or mental health needs experienced lowest levels of participation in decisions about their futures with a heavier reliance on birth parents and professionals to represent their views. Participation for young people with severe intellectual disabilities was generally restricted to decisions about daily living activities deemed by carers and social workers to be within their level of capacity and the boundaries of what they considered safe decisions, such as choosing food, clothes or outings. In some cases, pathway planning documents had been adapted to make them more accessible to young people with a range of communication needs, including a reduction in the size of the document and use of accessible language. However, such adaptation was not evident across Trusts and social workers indicated a need to improve the accessibility of pathway planning processes for care leavers with mental health and/or intellectual disabilities, reflecting social workers' knowledge of these young people to ensure an appropriate approach to communication and effective use of technology:

*We need something more tailor made for disability... Some of our kids can't write or read... and they're developmentally delayed in terms of their peers of the same biological age... If we had access to a tailored app that was on an iPad to work with our children in care, it would be great. Maybe there's things that they want to tell us that they maybe don't want to say out loud or there's a bit of embarrassment so it just gives them that wee bit more independence (Declan's social worker).*

In addition to facilitating more effective planning processes, such alternative approaches to communication could assist the development of rapport between social workers and young people and also help to increase their confidence to participate in decisions affecting their lives. Indeed, social workers repeatedly emphasised that for pathway planning to be effective, young people needed to be engaged and be at the centre of the process:

*If they are not able to participate, there is no point in proceeding with it because they are fundamental to it. It is their voice we want to hear in those pathway plans, it's not mine (Joanne's social worker).*

Several social workers described using more informal strategies to engage young people in the pathway planning process by working at the pace of the young person. They also held purposive discussions with care leavers in informal settings to inform pathway planning rather than arranging a formal meeting:

*One of the big difficulties particularly for those with borderline [impairments] is being able to pitch our statutory functions at a level that the young person is going to understand... One of the things that works well is non-direct communication. So sitting driving in the car and general chit chat is a much better way of working with Connie. She doesn't do formal interviews... Again it is down to communication (Connie's social worker).*

Some social workers also spent time with care leavers with mental health and/or intellectual disabilities to prepare them for pathway planning or review meetings and help them to share their views with other professionals:

*She comes to meetings... and I would always take a wee bit of time with her beforehand and just say, 'Now remember, you're able to speak really well and if you talk to people, just say what you need to say without getting angry... and they'll be able to hear you better, how you're feeling'. And if she's feeling stressed, we'll take a bit of time so that sort of settles and ease her into it and she is able to speak really well and she'll also put things down on paper for you. You'll say to her 'Write me out everything that is worrying you, everything that's concerning you' and we'll do it that way (Imogen's social worker).*

Indeed, spending time with young people and building a rapport with them was emphasised by social workers as a key foundation for effective pathway planning:

*Every young person is unique. Get in there, get to know them, get a level of trust and promote that they can achieve the optimal outcomes in their life... It's not about imposing my values or what I think they should be doing or achieving or what the Department's telling me they should be doing. It's about what do you want or what do you think you can achieve? And going for that and that's when good practice works best when you have the young person on board and they have ownership of it. If you haven't got that forget about it (Jake's social worker).*

In addition, social workers also described the need to have a sensitive approach to planning with young people who had overly ambitious future goals that needed to be balanced with consideration of risk and broken down into more realistic and manageable options:

*With a lot of our young people with learning disabilities... can really need support to identify what the future plans are going to look like and because of their high care needs that is directed for them because they maybe don't want to live in supported living but to keep them safe and to keep them well that level of support is something that they are going to need ongoing so living on the community on their own with our any supports isn't actually an option... You could ask them what their wishes are but you mightn't be able to go (Belinda's social worker).*

Social workers described the difficult task of balancing the rights of care leavers to make their own decisions with their need to assess and respond to risk. The capacity of the young person to understand choices and the consequences of their decisions or behaviours was an important issue. Some social workers indicated that care leavers who did not accept their level of impairment or refused to recognise challenges they faced were most likely to make unrealistic decisions for their futures.

Pathway plans were also regarded as somewhat redundant in terms of foreseeing the future and the unexpected changes that occur as young people leave care:

*It is quite a ridiculous thing 'Cos to sit and plan about what is going to happen when it might never happen... especially when leaving care... Stuff happens when it happens... There are lots of things you just can't plan for (David).*

Social workers and young people, therefore, emphasised that pathway plans needed to be timely, regularly reviewed and responsive to the changing needs of care leavers:

*It should have been every six months or something cos there was a lot of things happened in between... Just like me going mad or you know, stuff happened... They missed most of it... it's just me going on and doing it myself (Joel).*

A further challenge to the success of pathway planning was the context of limited resources or post-care service options. Formal plans could give young people a sense of security about what the future could hold for them and what supports may be in place as they move into adult life. However, in many cases, intentions documented in pathway plans changed or did not transpire for the young people often due to restricted resources or opportunities. For example, unavailability of preferred college courses due to over subscription or lack of choice about specialist placements due to limited provision and funding.

For those attending a special school or who were in receipt of children's disability services, transition planning had an added dimension as school staff and children's disability teams also developed a transition plan for leaving school and moving on from child to adult disability services. In some Trusts, transition coordinators within children's disability teams undertook these planning processes and coordinated the post-school plan. Some young people subject to these planning processes also had a pathway plan with the 16+ team and, therefore, experienced dual processes of both pathway planning and transition planning. For others, pathway plans had not been developed when the young person's lead social worker was from the children's disability service as the transition plan became the core planning document.

Despite involvement across 16+ services, children's disability services and transition coordinators, some young people experienced delays in transition planning. Several young people involved in the case studies who were due to leave school within six months did not have a transition plan. Their carers expressed concern that concrete plans for their move from school and care had not progressed despite upcoming transitions.

Given the variation in approaches, social workers indicated that a more joined up approach should be adopted across 16+ and children's disability services to avoid repetition and to streamline planning processes for young people and their families. Such collaborative working across disability and 16+ services offered opportunities to share more creative ways of undertaking person-centred plans for the transition from care into adult life.

#### **4.3.2 Preparation for Leaving Care**

The main focus of preparing young people for leaving care was developing their independent living skills for their eventual move from care, including teaching care leavers how to manage finances, grocery shop, plan meals and make health care appointments.



Most young people leaving foster care were encouraged by carers to become more self-sufficient to help them prepare for the practical challenges of adult life, although social workers noted that foster carers could also be over-protective and wary of allowing young people to undertake daily living tasks and social activities independently. Some young people availed of specialist support to learn independent living skills such as independent travel training provided by occupational therapy services.

There were also examples of young people leaving residential care being prepared to undertake more daily living tasks, although there was particular concern that young people in residential care became institutionalised and were not motivated to learn independent living skills:

*I was supposed to start cooking in the children's home and the chef there has cooked a meal. I'm not going to start cooking a meal when there is a meal sitting there you know... Like cooking and washing clothes they do try and sort of educate you on but for me the environment was completely wrong... the staff always wash your clothes... And then suddenly about six months before you move out you are like 'now you want me to do that?'... It needs to be done from the minute you go into residential care (David).*

Most young people emphasised the importance of having an opportunity to experience having full responsibility for a range of independent living tasks whilst still in care to allow them to practise doing things for themselves with support available, if needed:

*Being in care basically made me very mentally lazy in the sense of people doing things for me. So there's no reason for me to do them... Rather than you need this, this is how you go and get it... If you have any problems I will come with you but I am not going to do it for you. I think this is a major problem when it comes to young people in care... they go in expecting everything to be done for them, therefore, they become more reliant on other people and their independency in their own head is essentially taken away... If things hadn't been done for me I would have had to do them myself so I'd have had more time to prepare myself and I would have been in a much better position (Tony).*

Even when young people had accessed preparatory support from professionals and carers for independent living, they still often felt ill-prepared for adult life and struggled to put their learning into practice when they left care. Indeed, some 16+ social workers were shocked at the daily living skills young people lacked and their limited life experiences, including basic personal care.

Young people recommended that care leavers should gain direct experience of independent living to develop their daily living skills and learn from mistakes whilst still in care. Most young people advised other care leavers to be prepared for challenges and to use circles of support:

*Being able to take control of your own life... is enjoyable... but if you are moving out on your own don't be naive about it. It's not really easy... You have a lot of struggles. You have to budget... cook for yourself... Make sure that you are not being neglectful too... and don't break all the rules in the book by having a midnight party and getting thrown out the first week... make sure you have the support... cos it can be very lonely. And have good friends.... Make sure that you know you can tell them what's happening... Stay engaged [with 16+ services]... cos the more people you block out the more dangerous it gets for you (Louise).*

Many of the young people living independently had previously relied on carers or professionals to notice if they were unwell or if their health was deteriorating and had a new responsibility to attend to their own care needs. The importance of self-care was reiterated by several care leavers in addition

to caution regarding negative choices and influences young people can be susceptible to after care, as one young person indicated in his advice to other care leavers:

*Drink in moderation and don't take drugs. And just watch who you run about with cos not everyone is your mate. Look after your number one and don't give a f\*\*\* about anyone else (Jake).*

In addition to lack of daily living skills, young people felt they did not have necessary skills for engaging with professional agencies, for example, making medical appointments or addressing tenancy issues with housing agencies.

A range of courses were provided to assist care leavers to learn how to cope independently, however, some young people withdrew from these courses as they mainly involved care leavers engaged in substance misuse or criminal behaviour and were a negative peer influence:

*There was this independent living programme that I think was run by 16+ and I hated it. I went twice and didn't go back.... It was pointless cos the young people that were going to it just made it crap... They ruined it for themselves... I wasn't there to talk about drugs or how much you could drink in the weekend... (Chloe).*

Young people who felt inadequately prepared for living independently often described their leaving care experience as a sudden change from being dependent on carers or residential staff to having to rely on their own self-sufficiency. Those who had a more stepped exit from care, moving from care into intensive supported accommodation or supported lodging where carers or staff were available to provide regular advice and assistance as young people developed their independent living skills, were more satisfied with their preparation for their eventual move to independent living:

*When I moved in here I knew how to make toast and a pot noodle, and now I can make anything really... I hadn't a clue what you were meant to do with money... How to buy groceries... and how much electric you had to put on... I didn't just learn off the staff, I learned off the other young people as well... now I do my own cooking and my own washing... Just everything you would do normally in your own flat... It's really good... I thought leaving care was like literally they just stuck you in a flat... but it's not. There is staff here all the time. So if anything goes wrong... there is always somebody there... We do loads of fun stuff... and just have a bit of craic. You are never lonely because there is always somebody there (Laura).*

#### **4.3.3 Being Ready to Leave**

Young people were often anxious and stressed about their move from care, particularly for those with ASD who found it difficult to cope with uncertainty about the future:

*I started worrying about moving out two years before I actually moved out... The support worker at that time had tried to negotiate an extension to the time... to try and facilitate a longer phasing out period, which was completely denied (David).*

Many young people often reflected back that they had left care before they were really ready to move on. Young people sometimes exited care early on their own volition due to dissatisfaction with their placement or eagerness to live independently, but also due to a cessation of children's services, especially for those in residential or specialist care settings.

Some young people who left foster care later regretted leaving so quickly when they realised they were struggling to cope but returning to their former placement was usually not an option:

*I left so someone else could have what I had... If I could do it again I maybe wouldn't be in such a rush. I could still be at home [former foster care placement] now but I'm not... Someone else is in my place (Chloe).*

Young people advised other care leavers to stay with carers for as long as possible and keep in contact with former carers when they left care as they could be a valuable source of assistance during the transition to adult life:

*Don't [leave care]. Stay at home. I wish I had never left [foster care]... And don't burn your bridges either... don't fall out with your carers and keep on their good sides... That's what I think. They are your second support if you needed anything (Charlie).*

Young people leaving residential care were expected to leave care when they reached their 18th birthday, feeling they had limited choice and left care abruptly:

*I wanted to be independent quite quickly and I found out the hard way that I couldn't be... I think if I had of been more prepped for it, it would have been easier. But I kind of just turned 18 and went 'right you are 18 now there you go' (Tina).*

#### **4.3.4 Ongoing Support from Foster Carers**

By the end of the study, five young people over 18 were still living with foster carers under the GEM scheme. In these cases, carers continued to play an active caring role for young people and their relationships were described as long-term, family commitments.

A further 11 care leavers who had left their foster placements still kept in touch with their former carers who continued to be informal sources of emotional, practical and financial support. Indeed, some carers remained in daily or weekly contact with young people who had left their care:

*I go home [former foster placement] twice a week for dinner after tech... I can call in anytime I want... If they were going shopping or whatever at the weekend they would always ask me to go... I am not left out. I am going home for Christmas (Chloe).*

Even when care leavers experienced a reduction in contact with their former foster carers, they still played an important role in their lives which was very much appreciated by young people:

*He's always there when I want to talk. And I can say literally anything to him and he won't be offended... He's there no matter what... He would be my point of call... in the long term (Danny).*

Former carers often continued to be the main source of support for care leavers when their mental health deteriorated. The bonds developed with some carers extended well beyond formal roles specified by service boundaries and, for some, led to lifelong relationships and key sources of ongoing support. Indeed, in some cases, the continued relationship with foster carers could facilitate a return to live with former foster carers. For example, one young person left his long-term foster care placement at 18 but continued to enjoy a close bond with his foster mother and later returned to live with her when she became unwell.

The ongoing informal roles former foster carers played in the lives of care leavers were also noted by social workers who were also appreciative of contact with former carers who often shared concerns, provided support at times of crisis and updated social workers on the wellbeing of the young person.

However, these former carer roles were not formally acknowledged or funded by statutory 16+ services as part of their range a post-care services.

#### 4.3.5 Cessation of Children's Care Placements

There were two main issues relating to the cessation of children's residential care. Firstly, young people leaving mainstream residential children's homes had abrupt moves into independent or supported living following their 18th birthdays:

*You look at leaving care. You know you're part of a family in a sense. At age 18 in a conventional family do your parents throw you out? No. So there could be an easier transition from when you're in care... Foster children can stay until they're 21. Yet in a children's home... You're out when you're 18. It is ridiculous... May as well call it discrimination in a sense (David).*

Secondly, those moving from specialist children's disability or mental health settings to specialist adult residential care at 18 experienced considerable delays in decisions about such placements and uncertainty about their post-care futures.

For those in residential children's homes, the abrupt move from care on their 18th birthday was very difficult for young people with mental health and/or intellectual disabilities who rarely felt prepared to leave care and struggled to cope with independent living. Several social workers noted that moving on at 18 years is an unnatural transition too early in the life course of young people and reflected on the contrasting experience of young people in the general population who often continue to live with birth parents and avail of their support well into their young adult lives:

*18 is far too young to expect a young person to live independently... That is wrong and it has to change... A lot of young people leaving care and moving into independent living, really are struggling... A lot of them, if not most of them, have being set up to fail really... A young person leaving care at 18 in the first instance is hard enough... but if you've got mental health needs or learning disability or both, on top of that, to expect them to go out there at 18 and function in semi-supported or unsupported is a big ask (Joanne's social worker).*

*We're asking people to do it at 18, but people in the wider society maybe aren't doing it until their mid to late 20s (Tony's social worker).*

For those leaving specialist children's disability or mental health placements, although multi-disciplinary planning was undertaken, due to uncertainty about the availability or funding of adult placements, transitions were often rapid when prolonged decisions about care placements were swiftly confirmed as they reached 18 and had to leave children's residential settings:

*It was a bit rushed at the end... There was lots of planning and lots of discussion. Everything on paper, lots of meetings held. It got to the end and I was actually ringing up a lot saying 'Look we need to have something in place here. He doesn't know where he's going'... Time was running out although the planning and the discussions happened early (Sam's carer).*

Accelerated transitions from child to adult placements were often stressful for young people with intellectual disabilities and ASD. In several of these cases, despite timely planning meetings and assurances that a suitable placement would be secured, the decision on their accommodation and move to adult services was rushed, causing undue distress to the young person and their carers.

## SUMMARY

- The benefits of participation in pathway planning included: increased confidence, enhanced decision making capacity and improved outcomes as care leavers were fulfilling self-determined post-care goals. However, 16+ staff needed to undertake preparatory work with care leavers with mental health and/or intellectual disabilities to support their participation and utilise flexible and accessible approaches.
- While professionals aimed to ensure young people had as full a say as possible in decisions affecting their lives, care leavers with mental health and/or intellectual disabilities faced persistent barriers to participation including: communication challenges, capacity issues and funding delays. Some young people also found pathway planning processes to be redundant or patronising.
- Family members or carers often advocated on behalf of care leavers with mental health and/or intellectual disabilities. However, young people were also dissatisfied when family members, former carers and professionals dominated decisions about their lives, highlighting the importance of independent advocacy.
- Joining up planning processes across 16+ and children's disability services would help to streamline dual transition planning and ensure more accessible, person centred approaches.
- Preparation for leaving care included a focus on independent living skills, however, young people wanted to practise living independently whilst still in care.
- There was much concern for young people with mental health and/or intellectual disabilities who exited residential children's homes at 18 who did not have the adequate skills for independent living or access to informal community supports.
- Care leavers urged other young people with mental health and/or intellectual disabilities who were leaving care to make use of supports while they are available and not leave care hastily. Former foster carers often provided important ongoing support for young people post-care. These informal sources of support were valued but not formally recognised by 16+ services.
- Those transitioning from specialist child to adult placements underwent rapid, stress-inducing transitions due to uncertainty about the availability and funding of adult service placements.

## 4.4 POST-CARE LIVES

This section of the report examines the experiences of young people who had left care including accommodation options, financial struggles and engagement in education, training and employment. Young people's experiences of managing personal relationships, parenting and social networks when they had left care will also be explored. Furthermore, issues relating to vulnerability in young adult life, care leaver identities and stigma are highlighted. Support provided to care leavers from various agencies such as housing agencies, colleges or universities, voluntary sector providers and 16+ services will also be discussed.

### 4.4.1 Accommodation Options and Support

Types of accommodation available to care leavers were varied and ranged from staying with carers under the GEM (Going the Extra Mile) scheme, returning to birth families or moving to residential care facilities, supported accommodation or independent housing. The importance of stable housing was

emphasised by all respondents as a key priority before other post-care goals could be explored, as Jake's social worker explained:

*You need to have appropriate accommodation or you can forget about all the other elements of the care plan because if you don't have that stability of an appropriate placement a secure home environment you are really fighting a losing battle (Jake's social worker).*

### **Staying with carers**

At the beginning of the study, six young people were living with carers under the GEM (Going the Extra Mile) scheme. This number dropped to five during the study as two of the young women moved to independent or supported living arrangements and a young man moved back to his former carer's home from an independent tenancy.

Two young people availing of the GEM Scheme were living in kinship care arrangements with relatives and three were with non-relative foster carers and planned to stay there beyond the course of the GEM Scheme, as a permanent living arrangement:

*I don't think I have any worries about where I'm going to live it's always going to be here (Anna).*

However, the challenge for young people to adhere to the rules within the family home and for GEM carers to respect the young person's rights to live more independently as an adult needed to be carefully negotiated.

Social workers noted that two challenges for the GEM scheme were the reduction in financial support for carers and the requirement for the young person to be engaged in education, training or employment. However, when funding was secured and young people were engaged in education, training or employment, the positive benefits of the GEM scheme and shared care schemes under adult services were clear, with such placements providing continuity of care and accommodation for some time after leaving care.

### **Returning home to birth family**

Four care leavers were living with birth parents and/or siblings:

*I was kind of happy that I was moving back to my mum's... I knew where I was going (Alana).*

All of these young people had been diagnosed as having intellectual disabilities (co-existing with mental health need in one case). For others, returning home had been a short lived experience before moving on to independent accommodation.

Social workers commented on other cases where young people would have liked to return home but were not accepted by their birth families, due to their mental health or disability related needs or challenging behaviours. In some cases, care leavers who were looking forward to returning home but felt unexpectedly let down by their birth parents who then refused their return home. Conversely, some young people with mental health and/or intellectual disabilities were welcomed home but their parents were not able to meet their needs. In addition, several care leavers could not return home due to the risks they presented to younger siblings.

Whilst returning home presented an opportunity for reunification and informal support, it could also lead to strained family relationships and concern about the welfare of young people returning to

homes from which they were previously removed due to inadequate care or neglect/abuse. Some social workers expressed concerns about care leavers' vulnerability to manipulation or abuse on return home. In several cases, young people who returned to birth family were encouraged by birth families to disengage with 16+ services due to a desire to be independent from social services involvement. As a result, young people's access to ongoing support and advice was restricted.

### **Specialist adult residential care**

On leaving care, two young males moved from specialist children's residential care to specialist adult residential care settings following their 18<sup>th</sup> birthdays. These young people had severe intellectual disabilities, ASD and challenging behaviours. Much effort was made to create a smooth transition to help these young people cope with the challenge of a change of environment and routine, including use of staff handover visits, introductory stays and social stories<sup>9</sup>. However, confirmation of specialist adult care placements was often delayed until close to their 18th birthdays when young people had to leave their children's care placement and adult services formally assumed responsibility for the case. As noted earlier, this delayed decision making led to abrupt moves to new adult care placements and limited time to prepare young people for the transition. This level of ambiguity also caused great stress for parents/carers who were keen to make concrete plans for the young person's future. Indeed, for one of the young people who moved to a specialist adult placement, there was no guarantee that the young person would be able to stay in their new adult placement in the long-term due to funding issues that could result in a further move at age 25.

Another young person had a severe mental illness and moved from adolescent to adult psychiatric hospital care, before eventually moving to a supported living setting where she was the youngest resident (most other residents we also led to a risk of homelessness re aged 60+). She received support from her social worker and various other professionals in her first few weeks in this new setting, but felt that this support withdrew too quickly and she felt isolated:

*It was very lonely actually when I moved in first... you don't see the staff in here much... so it was kind of really hard for me... I know... they have to draw back at some point but maybe having someone around even if it wasn't a professional would have been good... All the people would be over 60's, mostly older people... I just spend a lot of time in my room (Louise).*

Social workers emphasised that the range of specialist, age appropriate accommodation for care leavers with mental health and/or intellectual disabilities was limited. In addition, young people with mental health and disability related needs who did not meet the eligibility criteria for adult services were often excluded entirely from access to specialist care settings.

### **Supported accommodation**

Six young people were living in supported accommodation at the end of the study. However, others also had previous experience of supported accommodation. Levels of support received in these settings ranged from intensive support in a secure home to medium or low levels of support with a view to enabling the young person to move to independent living.

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<sup>9</sup> Social stories are a practice approach with people with ASD and/or severe learning disability, providing short descriptions of a particular situation which include specific information about what to expect in that situation and why. In this case, social story work also involved the use of pictures of the new care placement and staff.

Two young people who had been diagnosed with severe intellectual disabilities and ASD and who displayed challenging behaviours transitioned to supported living settings where they shared accommodation with a very small number of other disabled young people and had access to high levels of staff supervision and support. One of these young people moved to this setting from a specialist children's residential home and the other from a specialist non-relative foster care home. Both of these young people expressed their contentment with living in these adult placements and enjoyed the increased freedom to manage tasks independently.

A third young person had moved to a supported living placement with residents who were mostly older disabled people. Whilst he appreciated assistance with maintaining his flat and daily living tasks, he felt there was an unnecessarily high level of professional involvement in his daily life, particularly protocols relating to his freedom of movement to and from the placement:

*Sometimes they like to know where I'm going... and just go through... three to four people... I get annoyed at that... It's my choice. They want to know because they can plan it then and make sure nothing goes wrong. But... I'm getting sick of it... I don't want to be depending on people all the time... and actually I want to be on my own (Simon).*

Other young people moved to intensive support placements for care leavers which were not part of the adult disability service and were usually commissioned from voluntary sector organisations. Young people in these settings accessed varying degrees of support from staff, as they developed their skills for independent living. Young people were very positive about their experience of these placements and the support available:

*I was actually very lucky to get into supported housing... Absolutely fantastic and I couldn't say a bad word about any of them... They helped with budgeting and just general maintenance and keeping your room clean (Tony).*

*It's really good. It's definitely one of my best placements... I have a flat here... There is somebody [staff] here all the time (Dawn).*

Many social workers also highlighted the valuable role of these intensive supported placements for care leavers with additional needs. However, there was concern that these placements were time limited as young people were expected to move on to independent living. For some young people with more complex support needs, longer stays in such settings were required. Social workers, therefore, recommended the expansion of such accommodation options in NI to offer a greater range of options and the opportunity for extended stays.

For those requiring less intensive support in supported housing, young people enjoyed a new sense of independence in these settings whilst also being able to avail of support when needed. For example, assistance to manage finances and tenancies. In addition to encouragement and support from staff to develop practical daily living skills, care leavers also accessed valuable reassurance and emotional support in these settings.

In most cases, young people viewed supported living as a temporary residence or a stepping stone to securing an independent home. For others, there were more abrupt moves from supported accommodation placements due to a breach of rules regarding maintenance of property or disruptive behaviours.

The main challenge for social workers in relation to supported living was the limited availability of such placements providing tailored support for young people with mental health and/or intellectual disabilities:



*A lot of the accommodation... with support on-site were for much, much older people... [or] beds were blocked... Our accommodation for care leavers will not take responsibility for medication... So there seems to be something failing our young people... or is it a case that we need something that has an age limit for 16-25 year olds?... You're trying to get something that has high support but keeps the young person integrated in the community and doesn't isolate them away (Sara's social worker).*

Uncertainty about the provision of supported living options meant that young people needed to be prepared to move when a placement became available, which may be earlier than expected.

### **Independent accommodation**

Twelve young people were living in independent rental accommodation during the study, either from private landlords or the Northern Ireland Housing Executive (NIHE), although social workers highlighted that securing a tenancy was often a challenge for care leavers due to stereotypical assumptions about their lifestyles and direct discrimination:

*A lot of our young people have that stigma that comes with them as care leavers. If we are giving them references or if the landlords become aware that they are from a care background, sometimes they say they don't want them (Sara's social worker).*

The majority of those living independently were struggling to manage financially. Those not as strained economically in the independent living group were young people receiving disability or mental health related social security benefits in addition to other care leaver entitlements. Most young people found that living independently was more challenging than they expected:

*Moving from there to living by myself, I definitely wouldn't say it has been the easiest thing by no means... Everyone, even I do, underestimates moving out by yourself. Just small things that you really need to focus on, like paying bills at the right time. Getting things sorted like heating, plumbing. Anything like that that goes wrong. Getting your food. Knowing what you should eat and what you should stay away from, all that sort of stuff... It's stressful (Tony).*

Many of those who moved to rental accommodation complained about the inadequate conditions of their home including essential appliances that needed repair and environmental issues. In addition to poor living conditions and being stretched financially, care leavers felt isolated due to living alone for the first time:

*The fire doesn't work. The heating doesn't work... the field mice... are in and out of everybody's flats... I am just here on my own... Sometimes it's lonely. I hate eating on my own. So I don't eat until I am home [visiting former carer] (Chloe).*

Some young people also felt unsafe in their homes and neighbourhoods as they were living in NIHE accommodation being used by other tenants for drug-taking and other anti-social behaviour.

Young people who had been diagnosed with an intellectual disability, ASD or mental health needs often struggled in terms of the practicalities of independent living skills. Some of these young people expressed uneasiness and lack of confidence about interacting with peers, agencies or professionals involved in their lives. Engaging with housing agencies was a new experience for young people leaving care and for some with mental health or intellectual disabilities, responding to these agencies was challenging:

*Trying to get some maintenance done in the house. I wouldn't necessarily have the best confidence going to my landlord and necessarily asking... I don't want to be annoying (David).*

### **Moving around and risk of homelessness**

Some young people had moved accommodation quite frequently after they left care. A sense of isolation and loneliness often affected young people's ability to settle in one place. Some care leavers who moved around had problems adhering to tenancy contracts or supported housing agreements due to their engagement in substance misuse or anti-social behaviour with a negative peer group. This led to lack of upkeep of the property or damage to the home.

Care leavers were particularly vulnerable to negative peer influence or exploitation, often due to a desire to avoid social isolation or loneliness, which increased their risk of housing instability:

*Learning disabled young people who have a smaller peer network maybe have to make themselves available to feel that they do have friends and can lead to further exploitation... We had a young person who lost their tenancy because others... exploited them and used it as a party house, caused criminal damage... He ended up in the juvenile justice centre... just that frustration of how they have been taken advantage of (Connie's social worker).*

Repeated house moves also led to a risk of homelessness which restricted their access to essential health services:

*Quite a lot of those with a mental health condition are transient because they... can't keep the people or the drugs from the door... Then they get into a spiral of complaints... and paramilitaries and then they get moved on... and they lose their benefits so just everything falls in. They can't register with a GP... or access supports for mental health (Laura's social worker).*

In the context of multiple moves across various short-term living arrangements, social workers indicated that the development of 'sticking support' services that stay with the young person during moves would be helpful, however, this would mean a shift away from workers covering a particular geographical area. Social workers also expressed concerns about cases where care leavers had been moved to temporary accommodation in bed and breakfast lodgings or in hostels due to a lack of alternative housing provision, which they deemed to be wholly inappropriate for young people leaving care.

There were particular concerns for care leavers with ongoing mental health needs including a lack of support for homeless care leavers with mental health needs and accommodation options for young people leaving mental health hospital care. Social workers also struggled to secure housing for care leavers who had a criminal history or who presented with sexual harmful behaviours or a history of arson, even when this was clearly associated with their time in residential care.

### **Support from housing services**

Under the Department for Social Development's 'Supporting People' programme (2003) in NI, funding is available to landlords and other housing providers, such as voluntary organisations, to deliver housing-related support services to enable vulnerable people to live independently. Housing-related support can be permanently attached to a particular tenancy (for example, supported living settings), or can be provided on a floating basis, linked to individuals rather than their accommodation, for a

period of up to two years. Social workers were very positive about the provision of floating support for care leavers and some care leavers had valued their support:

*They were brilliant... They came out every week to make sure I was doing what I was meant to be doing (Joel).*

However, for others, these floating services were sometimes limited and some care leavers experienced multiple changes in floating support due to staff turnover:

*I seen her [floating support worker] twice and then she went on maternity and then I seen another one... Then she moved away. And then I met somebody once that came to introduce herself and then left. And now there is somebody else that I haven't met. I don't really know because it's been over two years and I've maybe seen them three or four times (Chloe).*

The main provider of public sector rental accommodation for care leavers was the NI Housing Executive (NIHE). Social workers in 16+ teams had close working relationships with staff in the NIHE and often advocated on behalf of care leavers to secure housing for them. It was also noted that the point system of housing allocation used by the NIHE considered additional needs related to intellectual disability or mental ill health. However, social workers were concerned about restricted accommodation options for those aged 16-18 and the quality and availability of suitable housing for those over 18. Social workers reported gaps in the provision of accommodation, waiting lists for access to accommodation and poor repair of housing for those aged over 18.

Many young people's experiences of living in NIHE accommodation were unfavourable with unsatisfactory housing conditions, poor or delayed house repairs and slow responses to queries:

*It takes them weeks. I phoned them about a month ago to say the bin went missing... Nothing (Chloe).*

Social workers and PAs, therefore, often negotiated with the NIHE on behalf of care leavers to ensure necessary repairs were made to their homes.

In addition, social workers held concerns for some young people who were experiencing intimidation in the local community in which they were placed, including sectarian abuse and bullying on the grounds of disability or mental health. Several young people reported their fears of intimidation or abuse to housing agencies but did not have a positive response to their requests that their case be prioritised for a relocation to a new area despite their homes being attacked on several occasions and threats or actual physical attacks from members of the local community. Similarly, there was also a lack of confidence in the police service response to incidents of bullying or intimidation in the community:

*Basically I have been bullied my whole life... at school and then people from the church down the road started bullying me... Recently a guy stopped his car in the street honked his horn and shouted 'Get out of the town you f\*\*\*ing retard'... It makes me feel scared to go out on my own... I would always make sure I had someone with me... I keep looking over my shoulder every second... They have intimidated me in the shops before and the police don't want to do anything about it. I go to the police and apparently a threat to burn down your house is classified as free speech but I am seriously thinking if I said that to one of them coppers that wouldn't be free speech (Danny).*

## SUMMARY

- Young people who stayed with their former carers experienced consistent care and close foster family relationships.
- Those with more complex needs had secured specialist adult placements, however, there had been much uncertainty about the availability of these services and limited time to prepare for the move into these settings.
- Young people were often keen to move on to supported or independent accommodation to lead more self-determined lives, however, many struggled to maintain tenancies, were vulnerable to negative peer influence and found it difficult to cope with limited independent living skills.
- Some young people experienced high levels of social isolation and loneliness in independent living settings which impacted on their mental health.
- Some young people moved into NIHE homes or independent tenancies where broken equipment was not repaired in a timely manner and communication with housing agencies or landlords was challenging. Responses to requests for relocation due to abuse or intimidation in the local community were also slow and ineffective.
- There is a lack of supported accommodation options available for care leavers with additional needs with access to staff who have knowledge of disability and mental health issues.
- There were also particular groups of young people who were most difficult to accommodate including those aged 16-18, those engaged in substance misuse, those with a criminal record and those deemed to present with a risk to others. These groups of care leavers were at greatest risk of unregulated, temporary accommodation or homelessness.

### 4.4.2 Engagement in Employment, Education and Training

Just over half (n=16) of the young people in the case study sample were engaged in some form of formal education or training. Of the 16 in formal education or training, three young people were studying degree programmes at universities in NI and England. Eleven young people were attending college or employability courses with five completing GCSEs, A levels, access courses or NVQs at college and six completing essential skills or vocational qualifications at college or work training programmes supported by voluntary organisations such as Include Youth or the Prince's Trust, which offered personal development and employability skills training in preparation for mainstream training and work placements. A further two young people were still attending special schools and were expected to remain there until they were 19 years old, with both availing of taster sessions in work placements or at their local college. In addition, three young people who lived in specialist residential care accessed educational opportunities within their care placement that were pitched at their level of understanding and which were responsive to their behaviours

Most young people who were still engaged in college courses were enjoying the benefits of studying and socialising with peers:

*I'm getting on really well [at college]... It's right up my street and I enjoy it. Started it, haven't missed a day (Lorna).*

For some young people, participation in a college course marked a turning point in their lives where they established a core area of interest and future career path.

Young people engaged in supported work placements for adults with mental health and/or intellectual disabilities with support from voluntary organisations were enjoying experience of employment, learning new skills and forming new friendships at work.

The three young people studying at university highlighted the importance of encouragement and support from their PAs or social workers which facilitated their progress to university:

*I'm really glad that X [PA] told me to go [to university]... I would nearly call it one of the best experiences of my life, university life, especially when I had a whole socialising issue... We socialise at lunchtimes, coffee times... so it's not necessarily just class (David).*

However, managing the demands of balancing self-care with college or university work could also be challenging for care leavers with mental health needs:

*Uni is stressful... It's just hectic. Just so much work and placement as well... I really enjoy it... But... if I have hospital appointments... It's trying to get time off and... see my psychiatrist (Tina).*

Social workers commended young people who were successful in education or training programmes in the context of adversity. They also emphasised that smaller educational achievements (for example, completing a short course or level one NVQ) may not have as much recognition by those monitoring educational outcomes for care leavers as those who successfully completed higher level qualifications but were, nonetheless, significant achievements for the young person. Social workers also valued the employability and personal development courses offered by the voluntary sector but expressed some concern about the impact of budgetary cuts on the future of these services.

## **Employment**

Only five young people experienced paid employment. Only one of these young people was working full-time and by the end of the study had resigned from his position and was seeking new employment:

*It wasn't exactly the job that I had hoped it was going to turn out to be... Worrying about somebody constantly being on your back and watching what you were doing... It was a very high pressured job... So I have already handed my notice in (Tony).*

The other four young people were working part-time and two of these were working to support their studies at college/university.

Those who were working enjoyed responsibilities given to them at work, the extra income and the opportunity to form positive peer networks. However, they were also aware of the impact of employment-related stress on their mental health and had moved into jobs that were less demanding or were seeking alternative, less stressful employment options:

*I love it. I used to always do waitressing and it's so different... You have to put on a front... You always have to be at the top of your game. In [this job] you can relax a bit (Diane).*

Young people had also volunteered in various roles, often with a desire to help other vulnerable young people or to represent the rights of children in care.

Although low numbers of care leavers were engaged in employment, many of the young people engaged in education spoke of ambitions for future employment. Several were actively completing educational courses with a view to future careers in caring roles such as health and social care, social work, nursing or youth work. A number of those attending general work skills training courses or

supported placements were also keen to pursue work in hospitality, catering, hairdressing or beauty therapy.

In contrast, those who were not engaged in any education, training or employment were less clear about their career pathway and had limited or no plans to embark on any training or educational courses, with the exception of two young parents who still held clear ambitions for returning to education, training or employment when their children were school age.

Some young people found it difficult to make decisions about their future career pathway and repeatedly changed their course of study. Motivation and confidence were key factors impacting on young people's engagement in education, training or employment. Maintaining young people's interest in various courses and employability programmes was an important aspect of the work of the 16+ team which was difficult if courses were not pitched at the right level for the individual to challenge them to reach their full potential without overwhelming them.

### **Barriers to employment, education and training**

Overall, just under a third of the care leavers in the sample (n=9) were not in employment, education or training (NEET). The impact of impairment, disrupted schooling and adult lives and parenting were key barriers to participation in employment, education or training.

Ongoing mental health needs, anxieties and disabilities impacted on care leavers' opportunity to participate and maintain their employment or attendance at educational courses:

*I went back [to college] but I think I'm going to be kicked out... I was enjoying it I just had bad anxiety... if I don't go back this week I am going to get kicked out... Sometimes I feel like I just want to run out of the room... and don't come back (Joel).*

Non-attendance due to social anxieties or depression often led to suspension from college courses. Meeting the demands of course assessment and completion could also add to the high anxiety levels care leavers were already experiencing which could become overwhelming. Mental health needs linked to substance misuse also impacted on ability to sustain a job:

*I was actually doing quite well in my job at the time. I got promoted and I was being trained for another promotion... but then I started to take too many drugs and then the drugs were affecting my mental health. I developed anxiety and depression. I was going into work petrified, really scared... the doctor put me on the sick for six months but didn't give me no support whatsoever or anything else towards going back to work... [My employer] posted out my P45 in the post... I think they just says right 'she's not coming back, she's off too long' (Dawn).*

Some young people who were working to support their studies had ceased employment because of the impact on their mental health:

*I was working but not anymore... I worked for over a year... It was alright... I just had to leave... Because of sick lines, mental health... I was always so busy. I would have got out of Tech... and then straight to work... and maybe not getting home until eleven at night and then up again at half six the next morning. I hadn't time to sort anything in my head (Chloe).*

Several young people with mental health needs could not participate in mainstream, group based learning and opted out of education or training programmes. Some care leavers with social anxieties or low self-esteem also struggled to form and maintain friendships at school or college and were

anxious about social aspects of pursuing studies. When young people were finding it difficult to engage in education and with peers, support was important, however, such educational support was not always available. In addition, social workers noted cases where an episode of ill mental health at a key educational stage (e.g. exam periods) could impact on young people's long-term education and employment options.

Low self-esteem and confidence detrimentally impacted on care leavers' uptake of further education, training or employment and could be a particular issue for those with borderline impairments who felt they would not succeed in the absence of necessary support. Learning difficulties and lack of self-confidence also impacted on ability to complete forms to claim benefits and to succeed in formal interviews for course entry or employment.

Young people with intellectual disabilities required additional support in the workplace and not all employers were willing to meet their needs. Social workers also noted how some young people found it difficult to take direction from employers, particularly those who had an authoritarian approach, which impacted on their ability to maintain employment. Difficulties related to understanding employers' expectations and styles of communicating were also reported for young people with ASD which led to conflict in the workplace.

Social workers and other professionals provided support for some of these young people to enable them to engage with others in educational or employment settings which minimised the effects of impairment. In addition, social workers acknowledged that struggles with education or employment for disabled young people were not inevitable effects of impairment but the combination of a range of factors which negatively impacted on care leavers' education and training experiences including past trauma, disrupted early education and lack of informal family support. The approach of education and employment providers and their level of understanding and support was also critical.

Lack of access to more intensively supported employment was a significant barrier for those with more complex or multiple needs. Social workers indicated that there were more alternative pathways to further and higher education for those who had a diagnosed mental illness or disability, however, limited options were open to those without a diagnosis. There was concern again for those with borderline impairments who did not meet the criteria for specialist support.

For a small number of young people with severe mental health needs, engagement with education or work was not expected at the time of the study. Removal of expectations to engage in training or employment was welcomed by these young people given the high levels of trauma they had experienced and their ongoing struggle with mental ill health.

In addition to care leavers' own social anxieties and mental health needs, some care leavers' engagement in employment was restricted by professionals due to concerns about the risks they presented to others and the need for supervised contact with members of the public. When specialist provision was made available for those with support or supervision needs, there were also issues related to uptake of such services. Social workers acknowledged that there were a range of courses tailored to the needs of care leavers or disabled young people, but noted that some young people refused to access these courses as they wished to disassociate from the label of being a care leaver or disabled person.

The past and current disrupted lives of care leavers also continued to impact negatively on engagement in employment, education and training. Earlier disrupted education due to poor school attendance, health issues, bullying, challenging behaviour or ongoing family dysfunction had a long-term effect on care leavers' further engagement in education or employment:

*I moved schools eight times... so I never really got the chance to like make proper friends or even do school work altogether... I was moving so much... [I started but didn't finish] health and social care... and about ten other ones (Laura).*

*I went to Tech... to get you work placements and jobs but nothing like that happened for me... I didn't really feel comfortable around anyone after years of getting bullied quite a lot. So I just kept running away from things (Dawn).*

Previous experience of school disruption and bullying continued to be a feature of care leavers' experiences in further education opportunities as they had limited confidence in their ability to succeed educationally:

*I'm still kind of a bit lost... because I moved to a different town, I left school... There would have been a lot of fighting and stuff in school so I just didn't go... Most of my school would have been in juvenile justice centre... And so educational wise, I'm definitely not up to standard for this course whatsoever... I would rather just drop out than just fail it at the end anyway (Jake).*

Young people had often presented with challenging behaviours at school in response to bullying and challenges in their own lives which led to repeated suspensions or expulsion from school:

*All the bullying when I was in primary school and high school... til my temper burst and it didn't happen no more... Then I got kicked out of school (Imogen).*

The negative effect of poor relationships with peers and teachers and low expectations for care leavers' educational progress were also highlighted. Many care leavers left school with few academic qualifications which made it more difficult to progress to further education or employment. Disruption to schooling experience, leaving school early or without qualifications had a significant impact on progress to higher education or employment. As a result, many care leavers attended employability courses which offered work placement as part of their training courses which could lead to future employment. These employability programmes helped young people to develop their skills, confidence and experience for future employment, however, social workers were concerned that support for care leavers significantly reduced as they moved on from employability courses into further and higher education. In addition, those based in rural areas had fewer options than those in urban towns or cities.

For some care leavers, other priorities such as housing and personal safety, took precedence over education and employment:

*My grades all went downhill because of the problems going on at home. I didn't revise or anything... Everything was looking good but it all just completely went downhill (Norah).*

Some young people were also concerned that enrolling on courses would adversely affect their social security benefits.

Opportunity to gain work experience to build their CV was another issue raised by care leavers, particularly in the current context of economic recession and high rates of unemployment:

*I thought I wanted to do joinery but whenever I finished that there you had to get a work experience during that one year. Trying to get people into work experience is hard like. Then I passed it and all then the construction trade just went downhill, so it was a killer. Even like, if I had have approached somebody they would have said you have to have a minimum of 8 GCSEs (Jamie).*



High rates of youth unemployment in general also reduced opportunities for care leavers to secure employment as they were competing against others with higher qualifications, strong social and familial support and a greater range of prior work experience. Within this context, the additional support provided by voluntary and community agencies and the provision of work placements for care leavers within Trusts were particularly important.

Strained family relationships and ongoing personal difficulties (such as, experience of domestic violence) were also contributory factors for disengaging from employment, education or training. A further factor barring care leavers' progression in education, training and employment was ability to travel:

*He doesn't drive and transport is a major bar to... getting a lot of jobs... Even if he got his driving licence... the insurance would be £2,000 a year... He's looking at minimum wage stuff and by the time you've taken the cost of getting the bus up and back, he's working for very little. So he's really constricted to stuff locally (Tony's father).*

In addition, some care leavers did not feel confident travelling alone on public transport or could not afford regular public transport which detrimentally impacted on their ability to secure and maintain work.

Care leavers who were parents of young children also did not feel they could commit to study or work, given their caring roles. Focusing on effective parenting for young children and securing stable housing for their child was the main priority for all three parents in the study at the expense of their own education. Indeed, all three parents had withdrawn from college courses to meet the demands of parenting although they had plans to re-engage in further education when their young children were school age and their lives were somewhat more settled:

*I didn't realise how much written work was involved... It was a nightmare... There were days I was sitting with him in my hand holding the bottle, the laptop sitting at the side of me... it just got way too much... I was so tired all the time (Joanne).*

Unfortunately, care leavers who had taken time out of education or employment to look after their children were often over the age of 21 by the time they were ready to re-engage with education or training and, at that point, they could no longer access support from 16+ services. These care leavers felt they were disadvantaged by such age related policies which did not take into account the range of care leavers' personal circumstances:

*When you are 21 they close it unless you are in full-time education. I think that is wrong... I took a year out which turned into two years... so even when I go back to tech, I can't say I want my social worker back because it is not an option... which I don't think was very fair. Whereas if you are in full-time education you get to keep them until you are 25... If I wanted to I could have gone back but I wouldn't have got no finance, so I couldn't have afforded to go back even if I wanted. The child wouldn't have got his child care... I couldn't afford it, not on my budget (Jack).*

### **Support for education, training or employment**

There were a range of sources of financial and practical support for education, training and employment including support from: social workers and PAs in 16+ services; staff in schools, colleges and universities; and voluntary organisations. Some young people spoke highly of the support received from staff in these various services and their encouragement beyond educational or careers advice:

*They [16+ service] are getting me a laptop for starting my course. They are paying the bus up and down... in fact they done everything, driving lessons, theory, books you know? Everything that they thought would be beneficial to me, they would fund it (Norah).*

Employability schemes were particularly effective at supporting care leavers to develop skills for work and to secure placements which could lead to future employment opportunities:

*The employability team... got me a voluntary placement in the hospitals to do care work and they supported me through it... It looked really good on my CV for uni. The woman who did it with me, she was really good. She came down and spoke to the manager and explained it. And she would come down every couple of weeks and check that everything was ok. That was brilliant. It was really helpful (Tina).*

Most Trusts provided their own employability programmes, offering work placements for care leavers, however, there were concerns about the closure of these services in some Trusts. Some social workers felt that Trusts could offer more employment and training opportunities for care leavers.

Young people attending college received financial, practical and emotional support from 16+ teams who had developed good working relationships with course providers that helped to facilitate individualised support for care leavers. However, social workers indicated that more one-to-one tutor support or smaller group teaching would benefit care leavers who had limited experience of larger mainstream classes.

Young people attending university were supported by advisors in relation to all areas of their studies and pastoral care. They were provided with additional time, a private space for exams and note-takers, if required. At university, care leavers could access a financial bursary and tutoring to support their studies:

*[This university] is very good. There's a care leaver's bursary... that I don't have to pay back... I have a widening access officer because I'm... a care leaver. She's very good (Chloe).*

In contrast, one young person who had moved to England had difficulty accessing this support and struggled financially during her studies as she had not secured the bursary she was entitled to. Overall, however, respondents were positive about the 'Tick the Box' initiative. It encourages care experienced students to say they have been in care on their university application form, so that they can be informed of extra support provided by universities. Care leavers generally had individual education plans at college and staff understood their particular needs and offered some flexibility.

An important source of support for the care leavers with their accommodation, education, training and employment was the voluntary sector. Care leavers mentioned a total of 21 voluntary organisations or projects with which they were involved. These included charities concerned with supporting disabled people or those with mental health needs (such as Mencap, Positive Futures, the Orchardville Society, Praxis Care and Autism Initiatives); and charities that provided services for the leaving and in-care population (such as VOYPIC, Barnardos, Action for Children, Include Youth, Belfast Central Mission and MACS). Young people were generally referred to these organisations by their social workers or PAs and usually focused on particular aspects of their post-care lives relevant to the organisation, such as, housing, education, employment, health, or social inclusion.

VOYPIC (Voice of Young People in Care), a regional charity aimed at supporting and advocating for young people in care and leaving care, were the most commonly used voluntary organisation. The care leavers who connected with VOYPIC enjoyed being involved with this organisation and were engaged in mentoring, personal development activities, awareness raising, lobbying events, and social

opportunities. Some participants had been supported by VOYPIC through legal proceedings and several young people also undertook volunteer roles at VOYPIC. In this way, VOYPIC provided an opportunity for young people, not only to avail of support themselves, but also to offer it to others. Social workers also highlighted the benefits of ongoing floating support and accommodation provided for care leavers from MACS, BCM and Barnardo's. Some care leavers also completed work focused on drugs and alcohol awareness with DAISY, a project working in partnership with local charities (ASCERT and Opportunity Youth). For those engaged in youth justice, Extern and NIACRO also provided support services.

Several young people had contact with disability-related voluntary organisations such as Praxis Care, Autism Initiatives, Mencap, Autism NI and Positive Futures. Some were attending courses preparing them for job interviews, participating in work placements or social opportunities and accessing support with independent living. Social workers were also very positive about the opportunities offered by Orchardville and NOW for disabled care leavers, particularly in relation to developing young people's skills for employment. It was important, however, for disabled care leavers that these programmes were pitched appropriately and did not leave young people feeling overwhelmed or stressed.

In relation to mental health services, young people accessed a range of support from the voluntary sector including the Samaritans, Zest, Youth Life, Hurt, Lifeline, Contact NI and Yellow Ribbon. In addition, some young people with mental health needs availed of supported accommodation from Praxis Care or Mindwise and Threshold targeted at providing a stepped model of care for young people with mental health needs moving towards independent living.

Many young people accessing these services were very positive about the services accessed and social workers also noted their ability to offer more flexible services and provide consistency of services as young people transitioned into adult life:

*I have personally found Autism Initiatives an extremely helpful resource. They've carried on counselling and haven't stopped at 18 so young people can keep the same counsellor. They've done very well and they offer quite a lot of clubs at night and... get the older young people into volunteering themselves which promotes socialisation (Rick's social worker).*

Some young people had experienced delays in access to services from voluntary organisations. Indeed, there were concerns about the impact of financial cutbacks on the continued provision of valued services from the voluntary sector.

Interestingly, some care leavers chose not to have contact with care leaver or disability/mental health related voluntary sector organisations because they wanted to distance themselves from the stigma of associated with care experience, mental health or disability.

A final issue raised by social workers was the lack of voluntary sector services in more rural areas due to their centralisation in city areas.

When young people were not being supported to engage in education, training or employment at the age of 21, 16+ teams closed their case. There was much concern about the impact of this policy on those not engaged in employment, education or training who required ongoing support. Many of these young people had other priorities (e.g. housing, safety, health, parenting) on leaving care and were only in a position to progress to employment, education or training after they turned 21 but were no longer entitled to financial or other support from 16+ services. Social workers referred to

many cases that had closed at the age of 21 despite their desire to continue to support the young person to progress to employment, education or training.

#### **SUMMARY**

- The key barriers to participation in employment, education or training were: disrupted, negative school experiences; personal challenges post-transition from care; parenting, ill health and a lack of support mental health/disability related needs.
- Despite these obstacles, the majority of the sample were engaged in employment, education or training whilst others had a range of career ambitions but needed to overcome anxieties and develop their confidence for success.
- Care leavers gave several examples of financial, practical and emotional support received from social services, educational institutions and voluntary organisations. Considerable support was also received from family members and former carers.
- Promoting personal development and developing the self-confidence of young people to return to education and training was critical.
- There were concerns that access to support from 16+ services ceased at 21 if young people were not engaged in employment, education or training. More flexibility was required for these young people who would need access to 16+ resources post 21 when they had more time to re-engage in education, training or employment.
- The voluntary sector provided a wide range of services for young people across the sectors of leaving care, disability and mental health including assistance with training, personal development and employment skills.
- Young people also benefitted from social opportunities and mentoring roles where they could use their experience and skills to support other care leavers.
- Some young people, however, did not engage with these services preferring to disassociate from stigma related to being in care or having a disability or mental health need.
- Overall, it is clear that the voluntary sector makes a significant contribution to services for care leavers with mental health or intellectual disabilities that is much valued by young people and their social workers and requires ongoing investment.

#### **4.4.3 Managing Financially**

Financial insecurity and difficulties with budgeting were highlighted by care leavers who often felt ill prepared to manage finances independently when they left care. Young people explained that they had become accustomed to financial resources and material goods they had received whilst in care and after leaving, struggled financially to make ends meet on a greatly reduced income:

*They gave us £70 a month ... but then you don't get it... They are setting you up for a fall (Chloe).*

Difficulties relating to managing financially were not only personal or individual challenges but also reflected the context of economic recession, high unemployment rates for young people with mental health and/or intellectual disabilities, and complex social security benefit systems.

Most young people were in receipt of welfare benefits, such as, income support and housing benefit. Care leavers who were unemployed and actively seeking employment were often in receipt of Job Seeker's Allowance (JSA). Some young people could not work due to long-term illness, disability or mental ill health and were in receipt of the out-of-work benefit Employment and Support Allowance (ESA). In addition, a few young people were also entitled to Disability Living Allowance (DLA), several

were in receipt of child care benefits and one young person was receiving a carer's allowance. Young people with more severe levels of impairment who were living in high support residential settings also accessed disability benefits to support expensive care packages.

There was concern that care leavers could develop a dependency on social security benefit income which could lead to low levels of motivation to engage in further education or employment. For example, some care leavers only worked part-time hours so their benefit income would not be affected. Young also described being in a benefit trap:

*I am currently on the bru and basically I have been constantly applying myself to try and get a job and qualifications. But it's not an easy thing because of the way the system is designed. It's very hard to get out of that and actually get into a full-time course without losing my benefits, which obviously I need to support myself and this house (Tony).*

In addition to welfare benefits, young people who moved into independent living arrangements were entitled to financial support for setting up home from social services which often helped to buy essentials to furnish accommodation, including community care grants:

*When I moved into my first flat I was getting grants and money... 16+ get stuff like that. If they didn't I'd just be sitting there with a chair and nothing else... They had the money and stuff for me to get my bits and bobs of furniture and my bed and that (Jake).*

Several participants indicated that they had good knowledge of a range of sources of financial support and an ability to navigate the benefit system with ease. However, not all young people were aware of the regulations pertaining to claiming benefits and had built up significant fines or arrears which they were struggling to repay from already tight financial resources resulting in poverty and a risk of accruing further debt through loans to assist with demands for repayments:

*I had to add that [repayments for debt and rent arrears] on top of what I owed the Housing Executive... currently I am living on £63 per two weeks... which then reduces me to below what the government advises people should have to live on... At the moment it is really, really tight... What it comes down to is £20 goes on electric and gas, £20 goes on food for the two weeks and the other £20 is in case I run out of electric and cigarettes and that's it gone (Tony).*

*Finances is really hard. I'm on the dole. You don't get much money on the dole... I tried to save up every week for oil you know for the end of the month. I can't save, you can't once you get your shopping. You get... nappies and milk and food, you're skint... The social workers helped me get oil last month because I couldn't afford it at all. So they filled my tank for me (Sara).*

Lack of awareness of changes to benefits or entitlements could result in additional charges demonstrating the inflexibility of the benefit system and leaving some care leavers feeling wary of claiming further benefits. Young people were also not always aware of their entitlement to benefits. As managing financially was an ongoing challenge, young people required support from 16+ teams and family or friends:

*It was difficult at the very start because I mostly spent my money... X [social worker] had me on some kind of scheme where you learn... to budget out the money when you get your payment... it's getting better. I am going alright now (Charlie).*

*I am very bad with money... A friend would come over and say 'right, this is your money, this is how much you have and this is how long you need it to last... You need this amount of money for*

*food and then electric and gas and then this is the amount of money you have to spend'... I would have the idea of how it works, but how to actually do it, is a different thing (Tony).*

Most care leavers who were claiming benefits were assisted by their social workers, PAs or carers to liaise with social security and housing offices and process benefit claims:

*The social worker helped me as soon as I turned 18 to claim Job Seekers Allowance. He went with me to the first meeting to get it sorted out... My social workers would have seen how much money I was getting every two weeks and writing down a list of all the stuff I would need, like groceries, electric... So I wasn't just being fired in there and having to do it all myself. I wouldn't have been the best with money, I used to gamble a lot (Jamie).*

Access to information about entitlement for benefits and how to access them was also important as care leaver's needs changed. Care leavers with more complex needs were given additional support in terms of managing their finances, including assistance from staff in supported accommodation in terms of allocating money for household bills before spending on other items or social activities. Some care leavers availed of mainstream voluntary services in relation to financial difficulties including advice from the Citizen's Advice Bureau and Christians Against Poverty in relation to managing accrued debt and practical assistance from St Vincent de Paul including assistance with food and heating.

A few young people were assisted by their birth parent/sibling to manage their income. However, social workers expressed some concerns about family members managing the finances of care leavers, particularly in cases where family members had previously neglected or abused the young person. For young people deemed to lack capacity, social workers could refer to the Office of Care and Protection for assistance on managing these finances safely.

Social workers also found that some care leavers with mental health and/or intellectual disabilities who were not coping well, tended to disengage from services and support and were even less likely to maintain their finances. With incoming changes to the welfare system, there were also concerns about how welfare reform would impact financially on disabled care leavers. Several social workers highlighted the potential for direct payments and self-directed support to be used to develop individualised support for young people with mental health or intellectual disabilities. However, they reported a low uptake of such support for care leavers.

#### **SUMMARY**

- Care leavers were entitled to a range of benefits and accessed support from service providers, friends and family members to access benefits and manage their finances.
- Whilst some care leavers were managing their finances well despite very tight budgets others struggled financially and were at risk of poverty.
- Some young people were particularly vulnerable to financial exploitation from birth family members and other informal networks.
- Many young people accrued arrears on payments due to confusion about benefit regulations and struggled to pay back payments to housing agencies or the social security office. Others had taken out loans and accrued significant debts with repayments being difficult to manage on a limited income.
- There was limited awareness and uptake of direct payments or self-directed support to develop individualised packages of support.

#### 4.4.4 Social Lives

The range of social and leisure activities pursued by participants was varied including socialising with friends, sport and physical exercise, playing musical instruments and gaming. Some care leavers recognised the value of sport and keeping fit in terms of enjoyment and benefits to their physical and mental health. However, many young people struggled to feel motivated to regularly engage in exercise or sport. In addition, some young people were unable to access their preferred social or leisure activities when they reached 18 years as they were only available as a children's service.

Many participants enjoyed socialising with friends and nights out in local bars and night clubs. However, some young people who had ceased their use of drugs and alcohol deliberately avoided these social environments due to their link with previous substance misuse and peers who had a negative influence on them:

*The friends I was with, they were all drug dealers... I wouldn't really hang around with the same people that I used to... There was one particular friend who was my source to get the drugs... If he's getting you to sell drugs for him and you're taking drugs yourself you know it's not a friend... I just want to be away from it... I am just trying to do good now. I am just trying to forget about the past and look towards the future (Norah).*

Young people who had experienced bullying or abuse in their neighbourhood and/or had developed social anxiety were often reluctant to engage in social activities:

*My carer was too afraid to let me go out without anybody cos he had to follow three kids one day down a whole road that were going to attack me... I don't really have many friends... I rarely ever go at all and if I do I always make sure I have someone with me (Danny).*

In such cases, young people pursued individual interests in the privacy of their own home due to fears of being victimised in their local community.

Young people's mental ill health often impacted negatively on their self-confidence and skills for engaging socially. Young people's impairment could also impact on peer relations. For example, several young people with intellectual disabilities presented with challenging behaviours which were sometimes directed towards peers. Several young people with autism also had social anxieties and were unsure how to negotiate peer relations.

Interestingly, many young people enjoyed their relationships with animals and generally taking care of pets. Some young people spoke about the importance of their pets and how they often found comfort in spending time with pets and confiding in them and enjoyed caring for them.

Lack of independence in terms of having to rely on another person to drive or accompany them to an activity curtailed the social lives of some young people with intellectual disabilities. Independent travel training played an important role in assisting these young people to learn how to use public transport alone and independently attend various clubs and activities.

For a couple of care leavers with more severe levels of impairment, issues relating to risk and the sensory environment impacted on opportunities for engagement in mainstream social or leisure activity. For these young people, transitioning to specialist adult care facilities could open up new opportunities to re-engage with previous interests or social activities with the provision of appropriate levels of staff support and supervision.

## Social networks

Most care leavers had at least one person to whom they could turn to for support including family members, carers or friends. Some young people had several friends or acquaintances they associated with in their placement, school/college or work. Others had large peer networks but lacked a close friendship:

*I wouldn't have many friends that I would entirely trust is the best way I could put it (Tony).*

Several young people reported struggling in terms of forming and maintaining friendships. Many linked difficulties in this regard directly to their pre-care and in-care experiences and the challenge of trusting others:

*Nobody ever really sort of taught me how to socialise... I had a fear of socialising with people because every time I got to know somebody it seemed to be that I got hurt... I have to catch myself on... I could talk away to you but whether or not I'll actually strike up a friendship or trust is another thing (Lorna).*

Young people had often experienced school and care placement disruption in their personal lives during their time in care which had a negative impact on their ability to maintain long-term friendships:

*Every time you got close to somebody... another kid or a staff member would have got out or they were leaving to go home... it was just like, there's no point. And that's why I think I find it so hard now to form relationships with people, because everybody just seems to go (Joanne).*

When there were risk concerns for young people or others, opportunities for social independence were more restricted. Hospitalisation also hindered opportunities for forming friendships with peers. However, one young person had formed a close friendship with another in-patient during her time in hospital which was maintained following discharge. Similarly, some care leavers remained friends with young people they had met in children's residential homes and felt they had developed an affinity due to their common care experience:

*When I was in X [children's home] I made very good friends with a wee girl... She's my best friend ever. She doesn't really have much contact with her family and neither do I... She was a core part of me stopping drugs... We are kind of a distraction for each other (Laura).*

However, as young people moved to new places to live and pursued employment or education, it became harder for some to stay close with friends from their earlier placements. Disengagement from education, training or employment also limited opportunities for meeting new people and forming friendships.

As a result of all of the above challenges to forming positive and secure social relationships, social workers expressed concern about the danger of social isolation for disabled care leavers and the resultant lack of informal support from friends and family for some care leavers.

### 4.4.5 Personal Relationships, Vulnerability and Parenting

The majority of young people were single with only a few young people in settled personal relationships and living with their partners. These young people also enjoyed the support of their partner's family, which often contrasted starkly to limited levels of support provided by their own birth



families, and described their personal relationships as a source of healing due to the understanding and support they gained from their partner:

*I was going through my own personal troubles and she stuck by me. She's helped me a lot and I've never really had that before. So I appreciate it (Jake).*

Eleven young people had boyfriends or girlfriends, although most of these relationships were short-term and ended during the course of the study. Care leavers forming new relationships often felt they had to strike a balance between sharing information about their past and not 'scaring off' a new partner. For some young people, the challenge of personal relationships impacted on their own emotional wellbeing, particularly on their mental health when relationships ended:

*I found out that she was cheating on me... I was drinking every night and just being by myself. And then there was one night... I overdosed (Jamie).*

In a number of cases, care leavers with mental health and/or intellectual disabilities were vulnerable to manipulation or abuse in personal relationships. These young people (both male and female) had experienced negative personal relationships where they had been financially exploited, emotionally manipulated or had suffered serious domestic abuse. At the time of the study, several women were still struggling to move on from abusive personal relationships, following attempts to end contact with their ex-partners:

*That is quite a difficult situation basically because of his violence... I'm trying to break up with him... but he would harass me and ring me like 14 times a day... I have asked... about a restraining order... cos I would be a wee bit scared (Louise).*

Social workers and carers also held concerns about the capacity of care leavers with intellectual disabilities to fully understand the dangers of living in the community, leaving them more exposed to risks. Some care leavers who had moved to independent living were also targeted by other young people in the same housing or area. For example, young people had been taken advantage of by peers who borrowed money without repayment or stayed indefinitely in their homes, increasing their household bills and causing anti-social behaviour that put their tenancies at risk:

*I would have people phoning me constantly... It was my idiocy in the first place by lending them the money. So it is my fault that I didn't get the money back... I actually ended up getting a lot more taken off me but... I have learnt a lot... People can be a lot more deceptive than you think they are... I gained a lot more by losing people I thought were friends than I lost (Tony).*

Whilst birth parents or carers often expressed their worries about young people's vulnerability to exploitation, often due to their mental health and/or intellectual disabilities, care leavers frequently ignored their concerns or resented their intrusion in their personal lives. Social workers also noted how some young people could be vulnerable to exploitative and abusive personal relationships due to a desire to be loved and cared for:

*A lot of our young people are very needy and you know predators are very tuned in to this and because of their neediness then, they're able to be used and manipulated. I think it's a lack of confidence also, self-esteem too, it's almost like history repeating itself... It's the need to be loved at whatever price you know (Diane's social worker).*

There were particular concerns for care leavers with borderline impairments in terms of vulnerability to sexual and financial exploitation. Indeed, two young people with intellectual disabilities and severe mental health needs were involved in a police enquiry into child sexual exploitation. There were also

concerns about the vulnerability of young people via mobile and online technology. Some social workers considered these care leavers to be vulnerable adults yet found there was limited provision under vulnerable adult policy for these young people. Social workers noted that, whilst much effort was made to safeguard disabled children during their time in care with supervised contact and close monitoring of negative family dynamics, when young people turned 18 years old and were no longer within the remit of child protection law, more limited action was taken to protect them.

Whilst there were concerns about the lack of protection for these young people, there was also some evidence of over-protection for care leavers with intellectual disabilities living in supported accommodation with high levels of staff supervision and surveillance controlling their engagement in personal relationships. Their contact with partners was often monitored and controlled by staff or carers and they also had limited knowledge of safe sexual relationships and birth control. This over-concern for care leavers with intellectual disabilities is interesting as the same issues were relevant to care leavers with mental health needs or borderline impairments who equally lacked insight into safe personal relationships but were allowed to use their own agency to reject the advice and surveillance of staff.

Given the level of concern about negative peer and personal relationships, in some cases, social workers had sought to engage care leavers in preventive education programmes on safe relationships. However, in other cases where concerns were ongoing, no such direct work had been undertaken. Several social workers emphasised that such preventive and supportive work was essential for young adults with intellectual disabilities who were transitioning to more independent lives and negotiating personal relationships for the first time.

## **Parenting**

Three of the young people in the case study sample (one male and two females) were parents. All had full custody of their children and were living independently in rented homes with their young, pre-school aged children. All three parents were single at the start of the study, however, one parent re-established the relationship with their child's father. These parents had access to a number of sources of parenting support, including informal assistance from family and friends and community groups, including parenting programmes:

*My sister helped me out a lot when he was born... I didn't have a clue... She just came in and told me to go to bed and took him. She let me live with her... She just helped me out a lot. And then I finally got the hang of it myself... The course I'm doing is brilliant. It helps me. He goes to a wee crèche right next door and I be in for two hours and just talk about his behaviour and how to deal with it and his diet and all that. It's good... It's all wee girls that have wee babies too and they were in care (Sara).*

Informal support from family members or former carers including regular child minding and a range of practical and emotional support. In all three cases, their ex-partner's family played a key role as grandparents to their children in terms of child minding and practical support:

*My ex-partner's family help me out... Takes him once every weekend overnight and during the week if I need to go shopping or anything... Really helpful (Joanne).*

In one case, child care or protection processes were not in place. In this case, the 16+ social worker and former carers provided high levels of support for the care leaver, including assistance during episodes of mental ill health to enable her to continue with her parenting role. In the other two cases,

children were subject to a Care Order, although plans were underway to discharge the Order in both cases. Both parents had availed of emotional and practical support from family and child care services. However, these young parents were also pleased that social services involvement in their child's life was coming to an end:

*X's (child's) social worker is really really good... She will sit there and talk away to him and it's not about me and I like that... it's about making sure he's alright... She's very good... but I want him to have a normal life without having a social worker... I don't really need anything (Jack).*

Child protection involvement was often regarded by these parents as unwarranted and unnecessary. Indeed, both parents felt that they had been pre-judged as parents because of their own care history and their age or gender:

*I have never done anything wrong, it is just because I have a social worker myself... My son's first social worker... told me to give him up for adoption... because I was too young to be a dad... they were not going to give me the chance. I had to fight for that... I think her problem was she didn't think fellas could raise kids... (Jack).*

*I'm trying to be a good mummy but it's like they're not letting me be... If you were in care social workers don't let you try and be a mummy. They just be involved straight away and they don't give you a chance... They scare me. I don't want my child took off me... I have to tell them what I'm doing. I don't get to do nothing. It's like they're ruling my life... I cracked up the last time they were out... then they realised then what they were doing to me (Sara).*

Social workers concurred that care leavers who became parents were often under close surveillance due to their existing contact with social services and history of being in care, with rapid responses to issues that may go unnoticed for other young parents who have no pre-existing social services involvement. This over-scrutiny of care leavers' parenting ability indicates a risk averse approach to practice. However, 16+ social workers were also very aware that care leavers who were parenting needed support and, at times, specialist intervention.

When 16+ social workers had established trust based relationships with parenting care leavers, they were best placed to support parenting care leavers in their interactions with child protection teams and advocate for their access to a range of specialist support.

As noted earlier, parenting roles often led to care leaver's temporary disengagement from employment, education or training which impacted on their financial income:

*I love being a mummy but I would rather have waited and had him when I was a bit older... I just would rather have a job and all that... so I could like have more money you know to take him places and have a good life for him. It's not nice just lying about the house all the time and doing nothing (Sara).*

Parenting also impacted on their lives in other ways including their own mental health. For example, the negative effects of not taking her medication for mental ill health when pregnant or experiencing post-natal depression.

A further impact of parenting was the emotional impact of becoming a parent and care leavers' own recollections of their experiences of poor parenting. These memories affected their decisions about engaging in services that could support them in their parenting role.

#### **4.4.6 Identities, Self-esteem and Stigma**

During interviews with care leavers, social workers and PAs, key aspects of young people's identities often came to the fore including issues relating self-esteem, identities and stigma as they moved into their adult lives.

##### **Making sense of care identities**

A few young people presented as self-confident borne out of self-protection. These were skills developed as a result of prior negative family experiences and their time in care. They had also developed an understanding of their rights as young people and care leavers. Characteristic of most, however, was low self-esteem and self-confidence about their daily lives and progression into adulthood:

*I have such little confidence. I have been told that so much. But I don't know how to gain it... I am very self-conscious (Norah).*

Low self-esteem pervaded many areas of care leavers' lives, particularly their ability to form and maintain relationships and engage in social, education or employment opportunities. Some of these young people were daunted by the prospect of coping in adult life without the support they had become accustomed to in highly supported care environments. In contrast, care leavers with poor self-esteem could also be hardest to reach by service providers as they were unwilling or lacked motivation to engage with services.

Care leavers who had been living with kinship or non-relative foster families from a young age and were completely integrated into their families felt they were no different from other young people who were not care experienced. For young people who had spent most of their life in care but did not enjoy such stable placements, leaving care was more difficult and represented a loss of their care identity:

*Life in care is all I've known... And now there's nothing... because I've been in it for so long... now that I've left care, there's a big blockage... Now it's just what do I do you know?... What do normal people do?... I'd probably be classed as institutionalised (Jake).*

Whilst young people often did not wish to dwell on their care histories, preferring instead to look to the future and move on with their lives, they also needed to revisit and make sense of the past.

##### **Making sense of family identities**

For most young people, making sense of their family relationships was a core aspect of their identity. Many care leavers struggled to come to terms with negative family relationships and dynamics which persisted as they transitioned into young adult life; which some blamed themselves for. Young people had often spent many years trying to repair relationships with parents and who may themselves have experience of disability, mental illness and/or addiction. Making sense of the past and understanding family identity could also be more challenging for care leavers with mental health or intellectual disabilities who had been given more limited information about their background or support to understand their past lives.

The challenge of negotiating ongoing negative family relationships took its toll on the emotional wellbeing of care leavers. Some experienced a deterioration in their mental health as a direct result

of conflict with family members. Even for some of those young people who left care and returned to live with family members, the dynamics of their family relationships continued to have a negative impact on the emotional wellbeing of young people.

Many of the young people had experienced prior abuse perpetrated by parents, a factor which continued to impact on their present lives as young people tried to come to terms with past trauma. Similarly, some young people's recollections of abuse and neglect as young children persisted into their adult life as they continued to be affected by childhood memories.

Some care leavers had sought their care files so they could read about what had happened in their past that led to their entry to care and their family contact during care. Social workers were often concerned about how young people who react to case file content about their past experiences. However, it was important for most care leavers to have adequate information about their past to help them understand the reasons for their entry to care and to negotiate relationships with their birth families:

*I still struggle with childhood issues... I sort of haven't got over them but I've learned to live with them... I've asked the social worker and she's kind of explained stuff that I didn't really know from early on (Lorna).*

*Sometimes... it just upsets me... my mum told me in the past I got hit too when I was a baby. But in a way I like learning these. I like to know these things but in a way I don't and it upsets me to know it (Simon).*

Indeed, some care leavers displayed understanding and compassion regarding the factors which impacted on their parent's ability to care for them adequately, including mental health issues, domestic violence, substance misuse and parents' own prior experiences of childhood abuse and/or neglect. However, there was also a realisation that their parents had not provided adequate care for them or abandoned them:

*I know it was hard for her being a mum especially because my daddy was very abusive towards her... But at the same time you're sort of like I know what a mother should be and you're just not it (Joanne).*

*Dad was an alcoholic and was a gambler... with my mum it was mental health reasons. She couldn't help that obviously. But I always felt abandoned... I don't think I'll ever really get over it but I've certainly learned to live with it... There's days I feel worse than others (Lorna).*

In some cases, young people had ceased all contact with birth family as they were an ongoing source of considerable distress. The decision to withdraw from birth relations was often painful, but viewed as a necessary step to protect their own wellbeing and recovery:

*I haven't been in contact for over a year now... I actually just decided to give up on my family. So far it is helping. There's still times that you think about them and be sad and you have like emotional days. But it's a lot better me having that, than what I was going through with them (Dawn).*

Other care leavers still hoped for a reunion with family and hoped that dysfunctional family relationships could still be repaired. Carers commented on how young people felt torn between wanting a good relationship with their birth family and experiencing ongoing difficult birth family dynamics.

Social workers in 16+ teams were very aware of the self-esteem and confidence issues care leavers faced as they moved on from care and provided emotional support to enable young people to develop their understanding of past experiences and familial identities and develop more self-confidence in their young adult lives.

### **Stigma and care identities**

There were numerous examples of how young people identified themselves in terms of being care experienced, disabled or having a mental illness. Several felt a stigma relating to one or more of these identities and had multiple experiences of discrimination.

Many young people felt there was an ongoing legacy of their care experiences as they moved into adult life or felt stigmatised due to their care histories as people judged care leavers negatively due to common stereotypes of care leavers:

*They seem to tar us all with the same brush. They all think because we were in care that we're out to get people. We're causing trouble... They all think that we drink... but I think people need to change their view... They need to remember that it wasn't necessarily their fault... As soon as you say to somebody 'I was in care', they look at you funny as if 'oh we don't want her here' sort of thing. But... it's kind of got to the point where I don't care what they think, whether they're holding judgement or not (Lorna).*

Some young people were able to ignore such stereotypical and prejudicial behaviour, however, others felt a deep sense of injustice that all care leavers were automatically negatively labelled as trouble makers who would inevitably have poor mental health or substance misuse issues:

*It's 'Care leavers are the scum of the earth', definitely... That's unfair for the likes of me that have went through it and came out the other side good, you know, that haven't been involved in a criminal lifestyle, the drug taking and what not... They just see people in care but they don't take the time to find out why they are in that position... You get the feeling of segregation. It's just the feeling of not being normal (Jake).*

Participants faced these stereotypes as they left care and some experienced discrimination whilst attempting to secure a tenancy or job due to their care leaver status. Several young people also felt they were treated differently in public and by the police service:

*The sort of prejudice people have towards care leavers is ridiculous. Hence the reason why trying to find a house was so difficult. Everybody had these preconceived ideas that care leavers are partiers. They're criminals, you know, ridiculous things. Yet I'm a quiet person who likes my own company... and don't drink, don't smoke. You couldn't have a better tenant in a sense (David).*

*There is stigma with the police definitely... One night there was ones rowing and I was the one that got pulled to the side cos the policeman knew me from being in care... I was like 'I'm away. I didn't do anything' (Joel).*

Care leavers were also pitied by members of the general public due to inaccurate assumptions about care experiences:

*People feel sorry for you and I hate that. They go 'Oh that must have been really hard for you'. I'm going 'You don't know anything'... They would be like 'That's terrible. You were only a baby', I'm going 'I wasn't a baby.' Or when you don't speak to your parents 'That's horrible that you*

*don't have contact with your parents'. And I'm going 'It's just the norm'. I hate the way they look at you... I hate people feeling sorry for me (Chloe).*

Social workers were very aware of the stigma and discrimination care leavers encountered as they moved on from care:

*That sort of stigmatisation is something that is a shackle that is hard to get rid of. We have also quite extensive experience of landlords in particular who just refuse to provide for ex-care leavers, because they automatically associate them as bringing additional problems (Connie's social worker).*

As a result of stigma, some care leavers felt ashamed about their care background and saw it as a personal flaw they were unwilling to share with others which could also impact on their self-esteem:

*It seems like you've failed in life... like you're weak... You just feel like you're troubled. Like you're awful. Like you're a bad person... if you were in care. That's what other people looking in would think about it. How I feel other people look at it... It really is so embarrassing... I haven't told anyone in work... I wouldn't dare tell anybody because then I would feel I would be looked at differently (Norah).*

Participants generally did not share their care histories openly with others. Indeed, some wished to keep their past lives in care hidden from new friends or partners:

*The relationship is good but I haven't really told her about my past... I just don't like talking about it... don't really want to scare her just yet (Jamie).*

In addition, due to experience of discrimination, some young people did not disclose their care history to employers:

*The fact of just being a care leaver alone... there's prejudice attached... You're up to no good. I worked in a shop... and for a good three months they did not know I was from the children's home around the corner... I probably would have never got the job had I said I was from the children's home... When you move out of care... whether it's getting a job, whether it's going to find a house, if... you tell them you're a care leaver... unless they've been through it themselves they're thinking negatively (David).*

Many young people who wished to hide their care histories also disengaged from social services due to a desire to move on with their lives and disassociate from care related services. In contrast, care leavers who were more confident, felt able to challenge negative assumptions from peers and the general public. One young person, for example, challenged peers at college who held stereotypical assumptions about care experienced young people:

*I would tell people I was in care, it doesn't really bother me... There definitely is a stigma attached... We were sitting in tech and we were discussing people in care. It was so funny listening to them saying well they are going to end up with a mental health issues. And I said 'Well I haven't'. I have no problem telling them 'What makes you think that everyone that leaves care is going to be like that? And what makes you think that everyone that leaves care is going to abuse their children? It is just not the way it is'... That is bad (Jack).*

Several young people also indicated that their main advice they would offer to other care leavers would be to challenge the stigma and stereotypes commonly associated with care leavers:

*I think the label of being in care sticks to you... Don't let it label you and just go for it... Put two fingers up to everybody that says you can't and just go for it... It sounds cheesy but... don't carry it with you like a label. Just kind of make it part of you but not all of you (Tina).*

Such young people felt that being in care was part of their self-identity and made them stronger and motivated them to achieve more in life. A number of young people also felt their care experience directed them towards a career path that allowed them to help other vulnerable people in society. For example, care leavers indicated their care experiences had led to a desire to work in the areas of social work, criminal justice, mental health nursing and youth work:

*As regards to career path, obviously it's been really significant cos I've had the experiences of the criminal justice system and mental health services... That's what makes you who you are... Those things have really influenced what I want to do career wise... I've just really got a passion to help young people that are you know going through maybe a similar thing that I went through... Those would be kind of my goals (Louise).*

### **Stigma and disability**

Issues relating to disability and identity have been explored in the first section on the findings from the case studies. However, awareness of stigma regarding disability was also evident by disabled care leavers who felt they were treated differently because of their disability which could impact on their self-esteem:

*If the person with the disability sees that person staring at them... or talking about them it affects them and how they're feeling... That could put them down... But you just learn. You just let it go over your head because you don't know them people. It doesn't matter (Dawn).*

Therefore, in addition to hiding care identities, some disabled young people did not want new people in their lives to know about their impairments and, when possible, hid this part of her identity from peers and partners:

*I can hardly read and I cannot write properly... I can write text but the boyfriend doesn't know anything about this... If I was cooking and had to read the packet I would have to show my mummy... I don't like talking about it. I just keep it bottled in. Don't want anybody else knowing (Alana).*

*I keep both disability and being in care to myself... You don't want to tell everybody... You only tell people you know... It's private and it's just nothing to do with them. I want to be blended with everybody else (Simon).*

### **4.4.7 Hopes and Fears for the Future**

Young people interviewed were keen to discuss their futures, including their hopes and fears as they moved forward in their young adult lives.

Care leavers had a range of aspirations for their futures in terms of housing, education, employment, travel and personal relationships. Many young people expressed a desire to live independently in more suitable accommodation. Others were keen to progress to college or university:

*I would like to go to my own flat if I could because I can't have staff all my life (Sam).*



*University is just my focus now.... I never thought I would get to say 'Oh I'm going to uni'... So now that I can, I'm excited about it (Lorna).*

For others, ongoing struggles with mental ill health or addiction meant that the main priority was to have a healthy, settled life without stress after lives characterised by chaos and ill health. For these young people, an improvement in their mental health or ongoing abstinence from alcohol or drugs was their key objective.

*I hope I don't go to prison again because... stick to the job and just stay away from drugs... because I am a good worker and I think the drugs just kind of made you blind (Diane).*

*Hopefully at some stage my mental health will get a bit better and stabilise itself. We'll see how it goes. I just want to be normal. That's all I want (Tina).*

*I hope to get settled... I am always planning on moving... I am a very unsettled person (Joel).*

Young people who were living relatively stable lives in terms of accommodation and engagement in meaningful activities and solid support networks, were more likely to view their futures in a positive light. Others who were not progressing well in their transition from care held more limited hopes for their future.

Care leavers, however, also had fears and worries about several aspects of their future lives including: ongoing negative family dynamics; coping with the demands and responsibilities of adult life; failing to secure jobs or achieve educational aspirations; and ongoing mental ill health or substance misuse:

*I don't know what's going to happen and worried about what if it goes wrong... or how I'm gonna manage my money and stuff... If I do anything wrong with it, but people keep telling me that it's ok to make mistakes (Simon).*

*If I keep taking herbal [legal highs] all my mental health will be away with it... It's ruining me and it's ruining my mental health... If I keep going the way I'm going, I'm gonna end up dead (Susan).*

Some young people were also worried about losing support from 16+ services and other professionals involved in their lives, with fears about how they would cope on their own:

*The only worry is when I leave university and I lose the PA support that I have. That's probably the only thing... I don't even like thinking about it to be honest (David).*

Many care leavers were also worried about dealing with family issues and bereavement. Some care leavers had close bonds with older carers or relatives and were concerned about how they would manage when these sources of support ended.

In terms of moving away from carers to live independently, participants also worried that their transition was a 'one way street' with no return. As a result, leaving care was viewed as their one chance to make a success of their adult lives. For many young people, once they had left care and ended contact with 16+ services, there was no fall back to previous carers or support services should problems arise:

*If things go belly-up what do you do? I don't have a back-up plan. I've never had a back-up plan (Chloe).*

## **SUMMARY**

- Young people enjoyed varied social interests, however, social activities were hindered by social anxieties, risk concerns, inability to travel independently and issues relating to trust and poor self-esteem.
- Care leavers were vulnerable to negative peer influence, domestic violence and financial or sexual exploitation; however, they had limited access to preventive programmes to develop their awareness of forms of exploitation or abuse and to develop effective safety strategies.
- Some care leavers with intellectual disabilities felt over-protected which restricted their opportunities for social activities and to engage in personal relationships.
- All three parents in the sample had full custody of their children and were supported by social services, extended family members and former carers.
- Whilst social services provided a range of parenting supports, their involvement was often deemed to be intrusive as care leavers felt their parenting was under continual surveillance.
- As being a parent temporarily reduced engagement in education/employment, parents felt strongly that there should be more flexibility in access to 16+ services post 21 for parenting care leavers to enable them to re-engage in education, training and employment.
- The majority of care leavers had experienced stigma and discrimination on the basis of their care history which negatively impacted on their self-esteem as they moved into adult life.
- Stigma on the grounds of care identities and mental health and/or disability also led some care leavers to deny and hide both their impairment experience and their care history.
- For others, there was a sense of reclaiming their care identity and understanding how their care experience gave them particular strengths that would enhance their future lives and careers.
- Care leavers revisited their own childhood experiences and the reasons they came into care. Some established a place for birth family members in their lives, distant or close, whilst others accepted that relationships were not likely to improve and ceased all contact with birth families.
- Care leavers had varied ambitions for their future relating to relationships, housing, education and employment. Unfortunately, some were facing barriers to their future goals due to the legacy of their care experiences, limited peer networks, ongoing mental health or behavioural needs or a lack of qualifications/work experience. Worries for the future reflected these barriers and how they would cope when support previously received was reduced or ended.

## **4.5 SUPPORT SERVICES**

Care leavers in the study sample accessed a range of services as they transitioned to young adult life including: 16+ services; child and adult disability services; and child and adult mental health services. Some care leavers were also still in contact with youth justice services and several were receiving support from the voluntary sector.

### **4.5.1 Sixteen+ Services**

Care leavers, on reaching the age of 16, usually transitioned from their LAC social work team to the local 16+ team. Social workers and PAs from 16+ services then provided practical and emotional support for care leavers as they prepared to leave care and during the transition from care. They also

continued to offer support to care leavers until the age of 21 years or 24 if they remained in full time education. There was usually a period of handover from the LAC team to the 16+ social worker, however, limited resources and staff could result in delays to this usual process.

In some Trusts, if a disabled care leaver was accessing child or adult disability services, the disability social worker took the lead with the disabled young person only accessing a PA from the 16+ service. Some social workers indicated this approach was appropriate because there was no requirement for social work involvement from both teams. However, tensions regarding the roles and responsibilities of disability and 16+ social work teams were common. Interestingly, the same issues did not apply to care leavers in contact with mental health services as 16+ teams continued to assume lead responsibility for the case.

Some care leavers indicated that there was a reduction in 16+ support once they made the transition from care, particularly after their 18th birthday. Social workers concurred that there was a stronger focus on care leavers aged 16-18 years in 16+ teams because they were legally looked after and LAC procedures applied, including monthly statutory visits. In contrast, contact with care leavers over 18 years could be more minimal depending on their needs or willingness to access support. Some social workers were dissatisfied with this approach as they felt that those aged 18-21 years were often experiencing major transitions and required more support from the 16+ team.

The level of 16+ service involvement tended to reduce as the timing of case closure approached, that is, prior to the young person turning 21 years or 24 years if they were still in education, training or employment. In a small number of cases, there was ongoing intensive support from the 16+ service concentrated on a current issue or change in the young people's lives, such as placement moves or a mental health crisis.

In some cases, care leavers were keen for the 16+ service to cease if they felt they no longer needed their support or were dissatisfied with support from 16+ services. For some of these young people, their relationship with social services had always been fraught. In other cases, disengagement was related to their deteriorating mental health or engagement in risk-taking behaviours. Early disengagement from support services was concerning in cases where young people were deemed to lack independent living skills, had ongoing mental health needs or were deemed to be at risk in the community.

Indeed, one of the most common points of advice young people offered to other care leavers was to stay in contact with 16+ services and make use of all the practical and emotional support available to them:

*The advice I would just give is keep in contact with your 16+ workers. You don't have to contact them every day but they do help you... don't be just disappearing off the earth (Jamie).*

*Support is there to help you. I kind of felt like guilty for using it cos I felt like I wasn't deserving of it... Now I am looking back and think actually I really did need it and if it hadn't of been there I wouldn't be where I am now (Tina).*

Care leavers who ceased involvement earlier than expected were advised that, if they needed any advice in the future, they could contact the 16+ team again. However, most care leavers were reluctant to re-engage with 16+ teams as they saw it as a sign of failure. Social workers were often torn between their duty to support the young person but also to respect their right to refuse services:

*I find that quite difficult... 18 to 21 years olds... can choose to disengage but they remain open to us so we know that they need support but we have no way of giving that to them if they don't want it. It's a difficult one with our young adults (Tina's social worker).*

Some social workers noted that in such cases young people, the PA service would end with social workers following up on efforts to keep in touch. However, social workers noted that making multiple visits to young people who were not responding required additional time and social workers found they had to prioritise active cases where there was often a crisis to respond to.

Some young people recalled how the 16+ team used incentives to encourage them to engage with services, for example, access to financial entitlements. Staff in 16+ teams had a responsibility to 'keep in touch' with care leavers once every 28 days, even when young people were reluctant to engage with services. Most care leavers did continue with some level of contact with 16+ services whilst they were entitled to support:

*Generally there might be that period of disengagement post 18... There is a bit of resistance but also the young person realises... 'Okay these guys are here to help me, not just to give off to me'... particularly for the more vulnerable learning disability and mental health ones that period of getting to that understanding may be elongated (Connie's social worker).*

However, social workers also described cases where young people who did not respond their social worker's efforts to stay in contact. Social workers emphasised that a patient and sensitive approach was required when young people turned 18 and had a choice about ongoing involvement from social services.

In other cases where 16+ services were coming to an end at age 21 or 24, there were concerns that the withdrawal of services at this stage left care leavers in a vulnerable position with very limited formal or informal support in the community:

*There is a lack of provision and we are always looking for continuing services beyond 21. Just because you reach 21 doesn't mean that everything is fine... There are youngsters, particularly those who haven't got a roof over their head... or in and out of prison... They get lost and there isn't the wraparound service they need, perhaps they will need... I think 21 is still too young to go... When you think about your own children, they will always have a base for the rest of their life so what's the big magic age at 21 that you say bye bye and you don't see them again? But it makes the service stretched (Laura's social worker).*

Sixteen+ teams played an important role at this point as a main referral point to other services who could provide specialist support to meet the range of care leavers' needs. However, young people often found it difficult to engage with support from specialist agencies, lacking confidence in their ability to engage with unfamiliar professionals and organisations. For those who had close relationships with 16+ social workers, there was often a preference to draw on their emotional and practical support rather than accessing support from other sources. As a consequence, 16+ became a one-stop-shop of support for some young people.

The two main sources of professional support from 16+ teams were from a designated social worker and/or a PA. In most Trusts, it was common practice for all care leavers to have a named social worker. Whilst this is essential to meet statutory responsibilities for those still under 18 years, many over 18 still had a named social worker, even when a PA was involved with the case. However, at the time of interviews with social workers, there were plans to reduce social work involvement for those over 18 years and to rely more on PA support for older care leavers.

The decision to allocate a social worker and a PA to a case was usually based on the level of presenting risk or demands on the social worker's time due to the complexity of need or the young person's reliance on the social worker.

### **16+ social work role**

Most young people in the sample (n=23) had a designated 16+ social worker for part or all of the study. The cases of five of these young people were closed by the end of the study or were in the process of closing to 16+ social work because they were aged 21 years or over and were not in education, training or employment. Eight young people did not have a 16+ social worker although two of these young people did have a PA; four had no services from 16+ teams because they had a child or adult disability social worker and who solely led on their case; and the other two young people did not have a 16+ social worker because they were over 21 and not in education, training or employment. Although both of these two young people were disengaged from social work services, there were ongoing concerns about their vulnerability and emotional wellbeing.

Of those young people who had a designated 16+ social worker, most gave accounts of positive relationships with their 16+ social workers, citing multiple examples of the practical and emotional support they provided:

*She is just one of those people who... just tells you as it is. Usually social workers kind of dance around you a wee bit... But she just tells you 'Wee girl, wise up, what on earth are you doing?' I find that really helpful... I think she is my favourite social worker ever (Laura).*

*She's a really good social worker... I said to her about the advanced rent and she had it sorted within a week (Joanne).*

Many care leavers commented on the difference between 16+ services and LAC services, noting how 16+ social workers treated them more as adults and involved them in plans and decisions affecting their lives:

*I have a good relationship with my current social worker... He has dealt with me in a different way than all the past social workers have... Rather than going out and doing something for me, he would more encourage me to go out and do it myself. And that's a much more positive way to get someone to do something (Tony).*

Practical support and advice regarding housing, finances and further education/employment was a key aspect of 16+ social work support that many care leavers highlighted as particularly important as they learnt how to live independently. Many care leavers had accessed support regarding accommodation and education with assistance to find a place to live, funding to furnish their homes and support to enrol on training courses or work placements.

Some young people also highlighted that their 16+ social worker had gone 'above and beyond' the usual boundaries of the social work role to provide necessary timely support for them, demonstrating to care leavers that they genuinely cared for their wellbeing:

*She really looked after me. She was like a mum... I used to run away and overdose and stuff. If she heard I was in hospital she would have left meetings to come over. She was so, so really good and... if she had to go over work hours she didn't mind. She wasn't one of these people 'Oh I'm finished work, I don't think about ya'... How can you be like that?... She went the extra mile, she really did (Louise).*

*The social worker didn't have to do everything that she had done with me. She had done it out of the kindness of her own heart because as I say we got very close and she wanted to see the best for me herself. So the support I had from her was really helpful (Diane).*

Indeed, social workers indicated that working in 16+ teams required a particular skill set that is quite different to traditional family and child care practice and is more focused on working directly with young people in a flexible manner. Social workers highlighted the importance of understanding the reasons why some young people were difficult to engage with and having insight into the ongoing impact of past traumas and disrupted personal lives on their current relationships. Rapport and trust were essential to a successful working relationship between care leavers and social workers which was often best facilitated by a consistent relationship with the same social worker. Social workers found they needed to allow time for young people to engage at their own pace, to empower them to make choices and decisions, and to demonstrate persistence in their care for the young person.

For care leavers diagnosed with more severe and complex impairments who were living in specialist hospital or residential care, developing a relationship was often more challenging for social workers. However, in such cases, alternative methods could be used to develop a rapport, including observation in various settings, following the young person's lead and engaging in activities alongside the young people. One of the key threats to such close relationship building was a care management style of working where additional services were introduced to undertake different pieces of direct work with the young person and the social worker became a coordinator of services with less time available to spend with young people.

A further challenge to close working relationships was staff turnover. Some young people had experienced more consistency in social work services from the 16+ team than during their time in care:

*I would say there was a good 20 social workers. I would say in the one year I probably had about eight different ones. They were just coming in and going. That's what I liked about [social worker] at 16. He was there right up until I was 21, rather than all these changes. Because I'm not really good at meeting new people... You don't have to keep explaining yourself again. Like trying to get to know them. Trust would be a big thing for me (Jamie).*

However, others had experienced multiple changes to their assigned social worker. Social workers noted that repeated newly allocated workers could result in a loss of knowledge about the young person and gaps in care planning. Indeed, current social workers did not know why some actions indicated in care plans had not been implemented or why transition or pathway plans were not fully complete in case files before they had taken over responsibility of the case.

In several cases, the young person's social worker was on longer-term leave or had moved on to new employment. In these cases, another 16+ social worker or team leader provided temporary staff cover or assumed responsibility for the case or the allocated PA played a more significant role. This level of flexibility was important. As teams were relatively small in number, staff were often familiar with young people on each other's caseloads as they may have been previously assigned to them or knew the young people from their visits to the team office. Most team leaders had detailed knowledge of cases held by social workers and knew the young people in contact with their service. This level of knowledge and familiarity meant that team leaders could step in to provide temporary cover for staff and ensure a consistent service for the young person.

Some care leavers, however, had experienced consistency in the allocation of their social workers and came to rely heavily on their support. These care leavers were often anxious about ageing out of 16+ services and how they would cope independently when 16+ services were withdrawn:

*I love X [16+ social worker]. I am dreading what's going to happen when I do leave because she has been really supportive. Sometimes I don't have people to talk to... but sometimes it is good to talk to her as well. She understands. She knows everything (Norah).*

In contrast, several young people had less positive experiences of social work involvement, indicating that they felt their 16+ social worker could have given more financial or practical support when they were leaving care. One young person, however, emphasised the importance of clear communication with 16+ teams to ensure they fulfilled their expected roles in relation to care leavers:

*If it's coming up to a time where you know you're leaving and you have to sort something out, make sure you talk to your social worker and make sure your social worker is doing her job...correctly... My advice is just make sure your social worker gets a really plain clear point of what you want... Be straight, upfront and just be really clear (Diane).*

In addition to limited time to work directly with young people due to high caseloads, social workers identified a range of other challenges impacting on their role and highlighted, in particular, the lack of resources:

*Time is the main challenge... We need to spend more individual time with our young people... because that relationship that you build with them is going to be the positive thing that is going to help when they make changes in their own lives... but a lot of our work is crisis work (Laura's social worker).*

*There's no more money... Another way of avoiding cuts is by doing more so you're taking an extra age groups... We are really, really, really struggling at the minute with the financial resources... and every issue with regard to providing finances to young people seems to be a challenge (Charlie's social worker).*

Social workers also described the emotional impact of their work with care leavers, particularly in cases where they had concerns for the wellbeing of young people. Within the context of these pressures, staff in 16+ teams often had close working relationships and supported each other using a teamwork approach.

### **Personal Adviser (PA) role**

A total of 18 young people had a PA for at least part of the study. Social workers explained that there was always a named social worker for cases where there was high risk, however, in cases with low level needs, PAs could lead on the contact with the young person. Of the 13 young people who did not have an assigned PA, six had support from their social worker and two had exited the service. The other five had a child or disability social worker leading on their cases. These five young people came from two Trusts where disability services led on cases and co-working across disability and leaving care services was rare. In other Trusts, young people could avail of PA support alongside social work support from their disability service. However, in cases where PAs worked alongside adult disability services, there could be some confusion about their various roles. Despite these concerns about role boundaries, disability social workers emphasised the importance of disabled care leavers having access to a PA who could provide targeted support with housing, education and employment.

In terms of allocation to a PA, there was some variance in approach across teams and Trusts. Whilst most social workers indicated that PAs are allocated at 16 (except for qualifying care leavers who are not eligible) and continue to be involved at least until the young person is 21, others indicated that the PA was more focused on those who were 18 and over when they had left their care setting. One of the key challenges in the allocation of a PA was the level of demand and the shortage of PAs. In addition, staff turnover could also lead to delays in allocating a new PA.

For those who did have access to a PA, their role often involved practical support and advice alongside emotional support. Most young people gave positive accounts of their PAs:

*She's nice. We speak nearly every day... She'll do forms for me... Like applying for jobs and doing my CV and stuff with Tech. She would be in contact with the Tech quite a lot (Chloe).*

Indeed, some young people described more positive relationships with PAs than with their social workers, particularly regarding time spent with them and ease of access, often at short notice or during crisis periods:

*My PA would probably be more useful than my social worker... She's better at time keeping for one. She's more on the ball. She gets things done. He's just lackadaisical ... the PA... is doing stuff the social worker is supposed to do. I suppose they [social workers] have a way heavier workload with more people. And maybe doesn't get round to doing stuff or just can't be arsed. But the PA would do it for you (Jake).*

Interestingly, in a few cases, PAs had prior experience of working with young people in residential care and had the opportunity to develop long-term working relationships with these young people:

*I loved having her as my PA. When I was in the kids' home, she was an 'as and when' social worker there... So she's known me since I was 13... She helped me with finances... She was brilliant ... But every time she came out here we always ended up yacking about everything else rather than what we were supposed to be talking about... I see her like basically an older sister who helped me and she's very good to me (Joanne).*

Some care leavers who had strong relationships with PAs did not wish to engage with newly allocated PAs or other agencies. These young people were often also reluctant to turn to other specialist professionals for additional support. As a result, in a small number of cases due to cease at 21, PA support had continued for several months beyond the age of 21 due to ongoing support needs.

Contact with PAs varied across cases and over time, reflecting changing needs and the complexities of the young person's needs. The need for close collaboration between PAs and social workers was also highlighted. There was also some discussion of the informality of the relationship between PAs and young people, with PAs sometimes following up with young people beyond working hours. PAs highlighted the importance of building close, trust-based relationships with young people including befriending, advising and understanding their impairment related needs. Advocacy was also an important aspect of the role of PAs, however, some respondents indicated that since PAs were under the same 16+ team management as social workers, the extent of their independent advocacy role was weakened. Some young people and carers felt the PA service could be more effective at supporting care leavers if it was independent from 16+ social work services.

Whilst most care leavers had good working relationships with their PA, not every care leaver reported positive experiences of PA support. Some care leavers found their PA adopted an inflexible, procedural approach and failed to invest in their relationship. Others described their PAs as being overly-intrusive, reflecting their association with social services:



*She [PA] is not very good... I try not to see her... She just makes everything worse. She is really nosey and she needs to know everything that's going on... She is supposed to help you if you need forms filled in for the housing executive or community care grants... but she doesn't bother... She tells me to fill them in... She's interested in ticking her boxes and that's it. She is happy enough to shoot on again. She doesn't really care. I'm just a number on a file (Jack).*

Several PAs noted that 16+ resources tended to focus on care leavers most at risk whilst there should also be support for those who are settled but need encouragement and support to reach their full potential. PAs were also concerned that they would be expected to assume more responsibility for care leavers aged 18 and over who had less contact with social workers despite higher level needs at this stage of leaving care.

As some former foster carers played important, often unpaid and unrecognised, ongoing support roles for care leavers, social workers and PAs discussed the possibility of Person Specific PAs (PSPAs) drawn from the informal circles of support that care leavers were most likely to rely on. This form of PA support may be particularly helpful for those young people who wished to disengage from social services at 18 and disabled care leavers who could be supported by someone who already knows them well, however, it would carry additional administrative responsibilities for management.

#### **SUMMARY**

- Overall, experiences of 16+ services were favourable with some young people highlighting valued relationships and key supports from their 16+ service.
- Some young people felt their social worker or PA had gone above and beyond their expected role to support them, demonstrating genuine care and commitment.
- Care leavers liked how 16+ services treated them as adults and had less staff turnover than LAC services. However, some also identified examples of poorer practice where they felt their rights as adults were not respected and continued involvement with social services was either changeable or overly intrusive.
- It was reported that 16+ services focused on younger care leavers or those presenting with highest levels of need or risk resulting in reduced services for young people aged over 18.
- There was concern for young people with ongoing needs who disengaged from services. Encouraging these young people to avail of mainstream community supports or specialist services was emphasised, alongside the possibility of using personalised PAs to provide more individualised support for young people with mental health and/or intellectual disabilities.
- For those who need more time to find a secure place to live, negotiate post-care family relationships and learn how to cope independently, engagement in education, training or employment was only on the horizon at the age of 21. Therefore, respondents were concerned about the withdrawal of 16+ services at 21 and indicated a need to extend the service for some young people.

#### 4.5.2 Disability Services

Care leavers with intellectual disabilities could also potentially engage with child and/or adult disability services. This section of the report discusses the arrangements in place for these services, challenges with regard to access to these services and roles these service providers played in the lives of care leavers.

##### Children's disability services

In recent years, criteria for access to children's disability services has shifted to a focus on level of need for a service rather than severity of impairment. Their services include children's disability social work, nursing care and a range of family support up until their 18<sup>th</sup> birthday. Disabled young people can have access to children's disability services until they are 18 when they may transition to adult disability services if they meet their admissions criteria.

Some care leavers with borderline impairments, however, may struggle to gain access to children's disability services, particularly, if they were not known to children's disability teams prior to their 16th birthday. Social workers in 16+ teams also highlighted that it could be difficult to secure a diagnosis for care leavers when they were approaching adulthood and such assessments should be completed earlier in the child's life.

When disabled care leavers were known to 16+ and childhood disability services, there was variation across Trusts in terms of which team held lead responsibility. In some cases, children's disability teams took the lead for all LAC responsibilities and the transition to adult services, sometimes with assistance from a 16+ PA. However, in other cases, the 16+ social worker led on the case with input from children's disability services, when required. Social workers in 16+ teams were sometimes frustrated by the lack of involvement of children's disability services when the child clearly had disability related needs:

*Children's disability don't have a statutory responsibility... So I don't understand what the protocol is... we're [16+] the ones who have the responsibility of seeing them. They're not really supporting the family because they mightn't see them for six months... It's basically left with us... I'm probably not aware of all the different services or what funding they have (Linda's social worker).*

Likewise, staff in disability services found it difficult to access support from 16+ teams. Interestingly, in some cases, social workers noted that young people preferred to have 16+ lead on their case rather than receive disability services. Overall, staff in both 16+ and disability teams felt that it would be helpful if they could work more closely with children's disability services, even at the basic level of accessing specialist advice and guidance:

*I've never really interfaced with the disability team... In my experience... it's rare... but that probably would be a good thing for a wee bit more of a cross-over between those services... Even just in terms of advice from colleagues who know a wee bit more about... and sort of bounce off each other on things (Imogen's social worker).*

In the case study sample, ten young people assessed as having an intellectual disability had accessed children's disability services. These young people mostly had moderate or severe intellectual disabilities and had accessed a range of disability services including short breaks and transition support. Children's disability social workers fulfilled a range of roles for these young people including emotional support, access to counselling from psychology, placement monitoring and transition

coordination. Two young people with intellectual disabilities who did not access children's disability services had mild intellectual disabilities.

Some disabled care leavers seemed confused about the role of the various social workers involved in their lives. Other young people were more informed and positive about their involvement with children's disability services in terms of developing their understanding of impairment effects and strategies and skills to enhance independent living skills.

An important benefit of having involvement from children's disability service was the opportunity to be referred directly on to transition and adult disability services which helped to make a planned move to adult accommodation with assistance from a transition coordinator who worked in collaboration with school staff.

### **Adult disability services**

In our case studies, three of the ten young people who had accessed children's disability services did not transition to adult services and relied on 16+ services for professional support during their transition from care into young adult life. These young people did not access adult disability services for various reasons: one disengaged from social services; another had not yet aged into adult services; and a third refused a referral to adult disability services.

By the end of the study, seven of the ten young people accessing children's disability services had transferred to adult disability services and their case was being led by an adult disability social worker. Social workers indicated that, for those with a clear diagnosis of severe intellectual disability who were well known to disability services experienced the smoothest transition from child to adult disability services. In such cases, efforts were made to carefully plan for the move to adult services, particularly for young people with very complex needs and challenging behaviours who were moving from hospital based care to adult residential facilities. Such continuity of services from child to adult services was important and ongoing involvement with behavioural specialists and psychologists or psychiatrists who knew the young person well was very helpful.

However, social workers also indicated that there were considerable delays in response from adult disability services as young people turned 18 and moved from child to adult programmes of care. Even in cases where adult services were willing to accept the referral and had been informed of the placement needs of the young person, there was a delay in confirmation from adult services about the provision of services:

*I don't feel it's actioned well enough. A lot of this just is left to the last minute like going to the adult learning disability team. We have a number of young people who have had to wait for some time to get actually the support they need from them.... but they know they are coming over a year before so that should be put in to place (Jack's PA).*

*The problem is that the adult team have not properly dovetailed with us. They need to be involved and joint working with us from the age of 17 when they get the transition plan... Very rarely do we get anybody from their services starting to become involved... In fact it's the opposite. We're trying to hand over a baton to someone who's sprinting far away from us as quickly as possible rather than sprinting to us as quickly as possible (Johnny's social worker)*

Once accessed, social workers across disability and 16+ teams were aware of the benefits of the relationship with adult disability services. That included increased access to ongoing specialist support and a greater range of support options. Young people accessing adult disability services could continue

to avail of their PA from the 16+ service but it was adult disability services that took lead social work responsibility.

There were some concerns, however, about the more limited level of contact young people would have with their adult disability social worker compared to a social worker from the 16+ team. For those who did have access to adult disability services, contact with their social worker varied over time. Several young people who had transferred to adult services had had little contact with their adult social workers and, indeed, were unsure of the identity of their social worker.

Furthermore, parents and key workers in specialist adult residential disability placements were sometimes unaware of the identity of their social workers or the extent of their role. Due to the reduction in contact with a social worker when disabled young people transitioned to adult disability services, some respondents expressed a preference for continued involvement from the young person's PA.

In contrast to children's disability services, criteria for access to adult disability services was clearly based on level of impairment. Therefore, care leavers who had borderline or mild to moderate intellectual disabilities could not access adult disability services because they did not meet the eligibility criteria:

*Adult services are very, very tightly stretched... Some of our young people, they do have to be re-assessed again... If they don't meet the criteria for adult learning disability, which is an IQ of under 70, then they will not be accepted... For those care leavers, the case closes from us once they leave at 18 unfortunately... they're really falling between all those services... We haven't actually got a service within the Trust to refer them onto (Simon's social worker).*

In some cases, this meant that disabled young people who had accessed children's disability services had their level of impairment reassessed when they aged out of children's services and could not gain access to adult services. Indeed, some social workers found it difficult to secure an assessment of disability for young people ageing out of care:

*They come to us at 16... You find some of them have never been assessed for a disability and it's quite clear that they do have one and it can be very difficult to try and get that done. It's hard (Jamie's social worker).*

Delays in access to assessment had a significant impact on care leavers who were ageing out of children's services. A few social workers indicated that, even if the assessment resulted in a decision to refuse access to adult disability services, the information provided following the assessment could be useful for 16+ staff working with the young person.

For those who did not meet the criteria for access to disability services but had ongoing needs and borderline levels of impairment, the 16+ team was the main service provider:

*They don't meet learning disability but there's clearly issues... The need for routine... the limited skills... the behaviours... but they're on the cusp and just like a falling by the way side... They've slipped in between the net... It comes back to us again when they aren't classified in learning disability services... You can be stretched at times because you're putting out fires here.... and the skills you need to work with these guys with borderline learning disability is completely different ... but they're all falling into 16+ (Danny's social worker).*

Staff in 16+ teams, however, struggled to meet their specialist needs and indicated that these young people were falling through gaps in adult service provision. They also expressed concern for these care

leavers when 16+ services ceased as they were often not connected to any follow up specialist adult services:

*The young people who are really on the cusp of just not quite meeting that criteria for learning disability services but who you would see as extremely vulnerable... That would always be a concern for us when young people are coming to the end of their time with us and really aren't ready to be managing things without some sort of support (Imogen's social worker).*

### **Services for care leavers with ASD**

None of the care leavers whose main impairment type was ASD had accessed child or adult disability services; indicating a gap in specialist service provision for this group of young people:

*Even if they do have the diagnosis of autism, there is no services out there... and it's really difficult for young people with autism trying to link them in with education and training. They struggle with the group setting, they struggle with other people. They struggle with working in teams... I had a young person with autism on a work training programme and they were asked to leave because of their autistic behaviour (Norah's social worker).*

*I'm a bit confused about what services people with autistic spectrum disorder are entitled to... There's meant to be an autism co-ordinator in each Trust but I really don't know a lot about that. I suppose that says a lot about the whole thing (Charlie's social worker).*

Social workers explained that care leavers with ASD would not be eligible for disability services unless they had a co-existing intellectual or physical disability. These care leavers were, therefore, reliant on 16+ teams to meet the full range of their needs:

*Being autistic doesn't get you any additional supports... Autism is a grey area... You have to bolt on learning difficulties as well as the high end spectrum to get any additional supports... It does impair them in every aspect of their life, in terms of their social skills and their self-esteem and their ability to maintain accommodation and interact with outside agencies so we understand that but I suppose the system in terms of adult services doesn't understand... We just try as best we can to work with them but post 21 or if they are in full time education post 24 then they won't have a social work or PA service and it will be very difficult for them because the need is still there but they are not recognised in terms of any additional supports within the Trust (Jake's social worker).*

However, most social workers and PAs acknowledged they lacked knowledge of ASD and services available to meet their needs and expressed concern about this group of care leavers who usually did not meet the criteria for specialist services but also did not have their needs fully met in mainstream services for care leavers. Staff in 16+ teams also indicated that they needed more training to develop their own knowledge and understanding rather than learning by experience when they were allocated to a case of a care leavers with ASD or relying on advice from over-stretched autism teams:

*I had five young people with Asperger's and it was a learning curve for me cos I have never had training in that and actually I was learning from the young people. I was trying to get the ASD team on board... but getting them involved is a nightmare and even when they are involved getting them to do something is a nightmare (Jack's social worker).*

There were also concerns about delays in the assessment and diagnosis of ASD with several young people in the study were diagnosed with ASD well into their teenage years or as they prepared to

leave care. Young people diagnosed in their late teenage years often found it difficult to accept their ASD diagnosis and, as a result, disengaged from diagnostic assessments and disability services. Many social workers and PAs indicated that children in the care system should be prioritised for such diagnostic assessments to ensure care provided adequately met their needs and to facilitate early intervention.

In some Trusts, in response to the gap in provision for children and young people with ASD, one worker in children's disability teams was allocated to receive referrals for children with autism. However, this worker tended to play a signposting role, referring children for diagnostic assessment or to other autism services. In all Trusts, autism teams for both children and adults were established, however, these teams had a high number of referrals and focused on diagnosis and short-term interventions. Social workers recalled cases where young people with autism could not access necessary support and were at high risk in the community, with some drifting into the criminal justice sector:

*I have a case of a young person turned 18... He has quite severe Asperger's... When he met with people there had to be 3 people in the room... for safety as he could be quite violent... We felt he needed mental health support and the psychiatrist from the CAMHS team refused to back us and therefore his case was closed at CAMHS and he had no mental health support and that lad is now in X [juvenile justice centre]... This lad needs more... but we had terrible problems with them getting anything for him (Jack's social worker).*

*I had one guy... with Asperger's... He fell in with a really bad crowd and... did years in jail and he just fell right off (Charlie's social worker).*

Staff in 16+ teams were particularly concerned for care leavers with autism when the 16+ service ceased as there were no adult services to refer them on to:

*The hardest ones are autistic spectrum cos it doesn't fit into any category so it's very concerning. I do worry about our ones when they hit 21 because there's no clear Trust services that come in... Where do we send them to?... There is one social worker appointed for adult autism... in the whole Trust... She's obviously very busy... Autism is just a very good label but there's nothing really out there (Rick's social worker).*

In addition, social workers provided examples of young people with autism who presented with challenging behaviours due to frustration and lack of ability to cope in mainstream settings and, as a result, were missing out on key sources of support as professionals focused on their behaviour rather than their ASD related needs. Young people with autism who had a history of aggression, violence or criminal activity faced additional challenges as they moved on from leaving care services and had restricted access mainstream provision.

## SUMMARY

- Care leavers with intellectual disabilities could potentially access children's disability services until the age of 18 based on their level of need with access to transition support, short breaks and programmes to enhance their social and independent living skills.
- An important benefit of having involvement from the children's disability service was the opportunity to access transition services who helped with service co-ordination.
- When disabled care leavers were known to 16+ and childhood disability services, there was variation in terms of which team held lead responsibility. There is a lack of clear regional consistency about co-working arrangements across teams. Disabled care leavers were also confused about the role of the various social workers from each team.
- There was a general view that more collaborative working would be beneficial.
- Criteria for access to adult disability services was clearly based on level of impairment. Care leavers without a clear diagnosis or who had borderline or mild to moderate intellectual disabilities did not meet their eligibility criteria.
- There were often delays in assessments of disability for young people ageing out of care.
- Despite efforts to carefully plan for the move to adult services, particularly for young people with very complex needs who required specialist adult placements, there were often delays in confirmation about the provision of services from adult services.
- Once accessed, a key benefit of adult disability services was long-term access to a greater range of ongoing specialist support options. However, there were concerns about a low level of contact with care leavers compared to the regular contact provided by 16+ social workers.
- Young people accessing adult disability services could continue to avail of their PA from the 16+ service, however, adult disability services took lead social work responsibility for these young people from age 18.
- None of the care leavers whose main impairment type was ASD had accessed child or adult disability services, indicating a gap in specialist service provision for this group.
- Care leavers with autism, therefore, relied on 16+ teams to meet the full range of their needs where staff lacked specialist knowledge of ASD and related services.
- There were concerns about delays in the assessment and diagnosis of ASD which hindered the provision of early intervention to meet their needs.
- Autism teams were over-stretched and tended to play a signposting role, focusing on diagnosis and short-term interventions.
- Due to unmet need, social workers reported that care leavers with autism experienced negative outcomes, including a drift into the criminal justice sector and engagement in risky behaviours.

### 4.5.3 Mental Health Services

A total of 21 participants were in the mental health category and almost half of these young people (n=9) had co-existing intellectual disabilities and/or ASD. Only 10 of the 21 young people with identified mental health needs were accessing mental health services during the course of the study and all of these 10 young people were females.

Three young people were still accessing CAMHS as they were under 18 and all three had accessed adolescent psychiatric hospital care. One of these had co-existing ASD and one had co-existing

intellectual disability. Seven females were accessing AMHS with all but one having experienced a recent suicide attempt and admission to adolescent psychiatric hospital. None of these seven young people had co-existing disabilities.

The 11 young people with ongoing mental health needs who did not access formal mental health services included three females and eight males. Seven of these had co-existing disabilities and two had experienced a recent suicide attempt but had not engaged with AMHS as they did not find them helpful. A further two young people had prior experience of a recent suicide attempt and psychiatric hospital care but were not engaged with mental health services at the time of the study. Another young person (with co-existing ASD and intellectual disability) had been detained in a specialist adolescent psychiatric hospital but at 18 had moved to a therapeutic community setting.

This section of the report will outline young people's access to mental health services, including support from GPs and experiences of child and adult mental health services.

### **GP support for mental health needs**

In relation to mental health needs, most care leavers described their GPs as medication prescribers and/or referral agents. GPs tended to be the first port of call for care leavers during crisis events which triggered episodes of severe mental health deterioration and were the main gateway to referrals for adult mental health services. However, some care leavers who had moved to new areas were unsure about how to register with their GP. Social workers also highlighted difficulties with registration with a GP when they moved to a new area which restricted referral to other support services. Following a move, some care leavers also felt uneasy about contacting a new GP with whom they were unfamiliar:

*I didn't mind talking to my last doctor because I was going in whenever I had a problem but I don't know it's the first time going in and talking to this GP so I'm a wee bit iffy about going in (Jamie).*

Some young people felt their GP was too focused on prescribing medication whilst others had been encouraged to access counselling or therapy instead of relying on medication:

*I actually had to be put back on antidepressants and we're going through the stage of trying to get the right dose because too high and I'm like a zombie and I can't function properly... I hate with a passion medication tablets, I would go through quite a lot before I would even go to a doctor and look for antidepressants... I find it hard to sleep... but the doctor doesn't want to put me on pills cos he says I could get easily hooked on them... I understand where he is coming from (Danny).*

In some cases, young people refused such offers to be referred for counselling as they had extensive prior experience of ineffective counselling services whilst in care and would have preferred to have medication prescribed:

*He just says I'm really badly depressed and I've got anxiety. He said that he would rather me talk to somebody about it. But then I just says no because it was just my mood that day. I didn't even really want to talk to the doctor. But I've to go back up the doctor because I have to change my tablets because... the depression tablets aren't helping me at all (Sara).*

Others would have liked their GP to refer them on to therapeutic mental health services and review their medication but were advised to see their psychiatrist for changes to medication and referrals for additional support had not been made:



*My doctor would need to improve big time... She is like one of these doctors that doesn't want to give you anything... to calm me down... I tried to get them to change my medication but they won't... I'll see the consultant in a few months and see about my medication but it's only every six months you see him... I did ask the doctor to refer me... to CBT but she didn't refer me... They're useless (Joel).*

It is also important to note that some care leavers lacked a sound understanding of their condition or the need to consistently take prescribed medication:

*I am on anti-depressants but I haven't taken them in ages. I took them like twice. Two days and then I thought, I am not taking them (Chloe).*

In addition, some care leavers had chosen to refuse medication as they preferred to self-medicate using drugs:

*I was diagnosed with ADHD when I was 3 and then I went on medication... I was like a wee freak in school ticking and grunting and all, all the time. So I refused to take them... I have been smoking dope... It helps me (Diane).*

Social workers highlighted the important role GPs played in referring care leavers to mental health services. However, they were also often frustrated that these referrals had to come from a GP who may not be easily accessible to the young people or be familiar with the young person's care background or full history of mental ill health. The extent to which young people would openly discuss personal issues and mental health needs with GPs was limited in some cases. The 16+ social workers found it more difficult to support and advocate on behalf of care leavers if the young person did not consent to their involvement in the GP consultation. Some 16+ social workers also felt that GPs could be more open to communicating with them as part of a multi-disciplinary approach to supporting vulnerable care leavers who could pose a risk to themselves or others.

### **Child and Adolescent Mental Health Services (CAMHS)**

CAMHS are available in each Trust to meet the needs of children and young people with mental health needs, including care leavers. CAMHS adopts a tiered service approach ranging from low level, preventive services to specialist in-patient psychiatric care. Trusts also have provide LAC Specialist Therapeutic Support Services (TSS) for young people still in care, including those aged 16-18 years who are preparing to leave care.

Several young people did not find CAMHS helpful and had poor working relationships with their CAMHS worker:

*I've been seeing a psychologist about my mental health... I don't really see her much. I suppose when I do see her she doesn't actually give me that much advice or help... It's more so just try and do it yourself and you'll come round. Not very helpful at all (Imogen).*

*I don't like her [CAMHS worker]... every time I go, she thinks I am proper nuts. She is weird... And the doctor, I don't like him either... I find him really patronising. He talks to me as if I am a child... I see the psychiatrist once a week and the CAMHS worker once a week as well. And it is just assessment after assessment. Risk management and all of that (Laura).*

As a result, such young people disengaged from mental health services. Social workers also found that some young people who presented with more challenging behaviours were excluded from CAMHS.

Despite these experiences of inadequate or unhelpful CAMHS support, negative comments regarding this service were outweighed by reports of more positive experiences. Young people who had spent significant periods of time in children's psychiatric settings recalled invaluable support they received from CAMHS and valued their therapeutic approach, patience and consistency:

*It was scary [going into a children's psychiatric hospital]... but [you had] someone making sure you were ok and... looking after you and you weren't alone all the time. Those things just meant the world to me at the time... In hospital it was the people who... stayed up in the night, sat with me for many, many nights when I was really bad... I'll never forget those people who really did go out of their way for you (Louise).*

Social workers also commented positively on the range of work CAMHS undertook to support care leavers and noted that they worked flexibly at the young person's level and pace, often in partnership with 16+ teams. Indeed, this flexibility sometimes extended beyond the age of 18 if CAMHS were engaged in a programme of support for a young person or the care leaver was experiencing a crisis at the point of transition:

*They have been very good and the CAMHS team have kept on some of their cases just to take them over 18 and give us a wee bit more time to sort of feed things in or come to natural finish rather than having to finish at 18... I don't know if there's meant to be that leeway but there has been (Dawn's social worker).*

In addition to CAMHS, some young people accessed mental health support from LAC Specialist Therapeutic Support Services (TSS) whilst they were still in care and others sought support from community or voluntary services. Several young people had close working relationships with psychologist from TSS and valued counselling services from community-based organisations as they were independent from the Trust.

Social workers highlighted issues relating to access to CAMHS more generally, referring to waiting lists and delays for access to CAMHS:

*The waiting list to get into it the psychiatrist was horrific, terrible... I even physically went downstairs to the LAC Specialist service because he's entitled to those services as well to be met with blank looks and 'Sure we'll send you on an application form' which never arrived... CAMHS don't get involved in any learning disability cases... and it has been a nightmare (Johnny's social worker).*

There were particular concerns for care leavers who had co-existing intellectual disabilities for whom there was an over-reliance on psychiatric services in the intellectual disability sector to meet their mental health needs related to their care backgrounds rather than their intellectual disability. In contrast, young people with ASD who had mental health needs were directed by 16+ teams to CAMHS. Social workers also highlighted the limited range of in-patient care for young people in NI:

*The severe lack of inpatient treatment for young people with mental illness is worrying. We would have a lot of young people who would be very vulnerable who would be self-harming who would have suicidal ideation where you feel they just need to be in a safe place and it's very difficult because there is one unit for 16-18 year olds in the region. And if they don't meet the criteria for there again you're stuck with some very vulnerable young people specifically if they don't have the support (Lorna's social worker).*

One young person with an eating disorder was not able to access specialist care in NI and moved to a specialist hospital in England:

*There are no services over here so I was kinda just passed around like no one really knew what to do with me. Being in the adult ward was horrible, horrific... I was 13, 14... there just wasn't the room... in the CAMHS wards here... When I went over to England that wasn't the same.... if I hadn't of got that treatment I wouldn't be where I am now (Tina).*

On her return home after leaving hospital, this young person found that specialist services were still lacking in NI and waited some time for access to support services.

Social workers also indicated that those with undiagnosed mental illness were often not receiving CAMHS which often prioritised those at greatest risk. Lack of access to CAMHS for those with undiagnosed mental health conditions was problematic given that CAMHS were often reluctant to diagnose mental illness for care leavers, given their age and care backgrounds, which hindered their later access to AMHS:

*Most children go into care for neglect or abuse... and are not being diagnosed or assessed for their mental health or even talked about the issues around which they are been through or experienced... It's not saying they we want young people labelled as mental health cases but we want their needs recognised... and to be able to provide them with what they need... You are handling quite a bit of risk with cases as well (Jack's social worker).*

*A lot of these youngsters, although they have been in the system, nobody has stopped to diagnose them or they have got a half diagnosis... CAMHS are very reluctant. In fact they don't put a diagnosis on them, they wait til adult services but by that time if they don't engage with adult services they are struck off then they don't get a diagnosis and can't get a support package... They don't want a label because quite often conditions can change... but it's not a wrap around (Laura's social worker).*

These challenges relating to access to mental health services may reflect the demand for the service but social workers also indicated a professional hierarchy within mental health services, with psychiatry and psychology leading on decisions relating to who would gain entry to a service with little consideration of the social worker's perspective on the case. Interestingly, in Trusts where CAMHS were physically co-located with 16+ teams, close working relationships had developed across both services.

Encouraging young people to access CAMHS was an ongoing role for 16+ social workers and PAs with many acknowledging that some young people exited CAMHS too early due to their own disengagement from the service or because the intervention offered was time limited. Young people often found it difficult to maintain appointments with mental health professionals and engaged better when CAMHS made home or community based visits. Social workers highlighted that, for some young people with mental health needs, such outreach from CAMHS professionals should be more readily available:

*I do think CAMHS need to go out and do home visits. If we're able to go out, why are they not able to? ... As a rule, they don't do it... It would be easier for the young person if they were seen at home instead of being in a clinical environment (Norah's social worker).*

### **Adult Mental Health Services (AMHS)**

Seven care leavers were engaged with adult mental health services (AMHS) but often found it difficult to relate to professionals from this service. These care leavers had a range of mental illnesses including diagnoses of personality disorder, bi-polar affective disorder, eating disorder and depression. All seven

had also experienced psychiatric hospitalisation in relation to their mental illness, often associated with self-harm or suicide attempts.

Social workers expressed much concern for young people on their caseloads who did not transition to AMHS as they had not been diagnosed as having a specific mental health disorder and had a history of disengagement from mental health services or moved in and out of mental health services only availing of short-term interventions:

*There's a lot of our young people would fall between a rock and a hard place where they have mental health issues but no mental illness... You have a lot of young people where there's no diagnosis and they don't meet the criteria to be referred to a community mental health team but are very clearly very vulnerable young people. There's maybe a lot of self-harming, suicidal ideation but there is no mental illness and they're the young people that we really, really worry about... That's why staff feel very responsible. We've had a lot of young people we've walked away and thought will they still be breathing in the morning? (Lorna's social worker).*

There was also frustration amongst social workers who had genuine concerns for care leavers' wellbeing but could not refer to AMHS directly. In such cases, 16+ social workers had to persuade young people to attend their GP to seek a referral to AMHS which was often challenging if they were experiencing low mood, depression or agoraphobia.

Care leavers who had moved from CAMHS to AMHS had mixed transition experiences. Some had experienced gradual changeovers from one service to the other whilst others had little preparation. Young people also experienced delays in access to AMHS due to lengthy waiting lists which impacted negatively on their ongoing mental ill health. Many 16+ social workers advocated on behalf of young people, with their consent, for access to AMHS and followed up on slow responses to referrals for support from AMHS.

When care leavers did eventually gain access to AMHS, a 'three strikes and you're out' practice was usually adopted whereby failure to attend three appointments resulted in discharge and a need to seek a new referral via the GP. As a result, many care leavers indicated that AMHS was inflexible and did not take into account the needs of care leavers:

*There was one appointment with AMHS... for half nine in the morning and I wasn't driving and there is no buses out of here at that time of the morning... I phoned up and told them that I couldn't make it and they said they would send me out another appointment but they didn't... Then they just cut me off... I don't really like her [CPN]... She came in here and she was accusing me of smoking grass... I don't even smoke grass... I don't even smoke... so I don't see mental health now (Joel).*

16+ staff also expressed their dissatisfaction with the routine practice of AMHS closing cases when care leavers missed three appointments and an inflexible approach to working with care leavers:

*I have problems with the mental health service which is basically two missed appointments and you're out and then it's back through the GP and then they are waiting on another referral letter to come back out and too much time passes... if somebody is that low (David's PA).*

*The transition from children to adult services is nothing short of abominable in my view... Age doesn't negate any sort of mental health issue, in fact it exacerbates it in that there maybe isn't accessibility to services at 18... Yet our 18 years olds who have mental health problems... may feel they don't want the help even though they may require it and it's assessed that they do require it but because they don't attend, services are withdrawn, so that lack of reaching out to offer*

*services is very curtailed for care leavers within the adult mental health world (Connie's social worker).*

Due to this practice, 16+ social workers regularly reminded care leavers about upcoming appointments by telephone and often assisted care leavers to travel to appointments or accompanied them for additional support. Social workers also highlighted how AMHS usually expected young people to attend appointments in their clinic which were difficult for some care leavers with particular mental health needs to attend rather than providing home-based appointments. Some social workers also felt that the stigma associated with AMHS influenced young people's willingness to engage.

Social workers emphasised that, as there was ongoing corporate parenting responsibility for care leavers, there should be a presumption of their vulnerability to mental health issues:

*There seems to be too many parts of the system that the focus is keeping people out or passing on, signposting. It's a polite term for passing the buck... I'm sure they've waiting lists as long as your arm and they have to do the best they can within their own system but there just needs to be something additional, some recognition that care leavers have those additional barriers (Charlie's social worker).*

There was also a clear message that a more flexible approach to mental health services at least up to the age of 25 was needed:

*The transition from CAMHS to adult is horrific... Especially after being in hospital for so long when you turn 18 you are not 18 you know what I mean? You are not an adult. You're... not ready to make your own decisions. And I just think that CAMHS need to be higher [in terms of leaving age] when you have got mental health issues. It's a problem with your mind so how can you be expected to be an adult when you know your mind is not in the state of an adult? (Tina).*

In addition to waiting to receive services for an extensive period of time, young people were often dissatisfied with adult services they eventually accessed. Many young people reported AMHS to have a 'cold' and 'clinical' focus in contrast to the therapeutic approach in CAMHS. Young people found AMHS to have an over-emphasis on medication and risk of harm or suicide, rather than assessing their mental health needs holistically. In addition to a shift from therapeutic to a clinical focus, young people noted the reduced time available with AMHS professionals:

*The mental health service was good up until I turned 18 and then when I went to AMHS... It's ok if you were very suicidal or whatever, it's definitely not the sort of place I would advise you to go and seek advice or support... You are in 15 minutes maybe and the whole time all they'll do is talk about what changes they can make to your medication... There's no outreach service... There's no connection there ... He doesn't talk to you about what's actually going on with you (Joanne).*

Young people also preferred how CAMHS was a 'one stop shop' in terms of mental health service provision, providing both medical and therapeutic support in one building with the involvement of a low number of professionals. Care leavers who were transitioning to AMHS often commented on the difficulties associated with being required to tell their stories yet again to unfamiliar professionals, reliving painful experiences:

*I was offered six weeks counselling and would see them. Then the doctor would refer... for more counselling and then I would go to a different counsellor for another short period of time. And during this time I would literally have to... rehearse my life story. And to be honest, it got really annoying...I just don't bother with it because I'm not going to, every six weeks... go over my life story again to some new stranger (David).*

Young people transitioning from CAMHS to AMHS noted a stark change in service culture and gaps in the provision of therapeutic services. Many social workers also felt that AMHS provided a reduced level of service for young people compared to CAMHS and often failed to meet the needs of care leavers:

*CAMHS is far easier to talk to... They are more relaxed there... It's a lot easier to talk to them, to build a relationship with them. But with AMHS, they don't come across as friendly... if someone isn't ready for it, it will be too much for them... very professional. They are not comfortable to sit around. So I just go in and pace about the room... CAMHS is far more in depth with people. CAMHS go far more into people's lives and issues and problems and when you're young coming from a child's clinic to an adult's clinic there's gaps... Even though I was referred by the doctor I was seeing for all those years, the adult clinic kind of never took me seriously (Diane).*

Disengagement from AMHS was a common reaction from young people who found the service culture clinical and lacking in therapeutic support for care leavers. It is concerning that many care leavers with serious ongoing mental health needs decide not to avail of AMHS because they did not see any benefit from accessing a limited mental health service. Due to disengagement from AMHS, some care leavers developed their own strategies for coping with mental health difficulties. For some, this meant a reliance on their 16+ service for support with mental health needs, resorting to informal emotional support from former carers or self-medicating.

Social workers in 16+ teams also felt uneasy about young people depending on them for all types of support instead of accessing specialist mental health services. In such situations, social workers were holding high level risks. Having sole responsibility for the welfare of young people with deteriorating mental illness or at risk of suicide was a challenging experience for 16+ social workers who were deeply concerned about some young people on their caseloads. The lack of access to AMHS was also worrying for young people who were ageing out of 16+ services.

A further gap in provision for care leavers who had transitioned to adult services was the lack of support available for those with substance misuse issues in addition to mental health needs. AMHS often refused services for these young people because their mental health needs were drug or alcohol related. However, 16+ social workers identified substance misuse as a very common feature of the lives of care leavers who required specialist mental health services.

Social workers also felt that there was a professional hierarchy within AMHS with medical professionals dominating assessments and decisions with minimal sharing of information from AMHS to 16+ social workers who were most familiar with the needs of care leavers. Social workers in 16+ teams attended review meetings in AMHS for young people on their caseloads, however, they indicated a need for more proactive co-working efforts from AMHS. Such partnership approaches could offer support for staff in AMHS who were less experienced at working with care leavers and, vice versa, provide specialist mental health advice for 16+ teams.

## SUMMARY

- In relation to mental health, care leavers identified their GP's role as prescribers of medication or referral agents to mental health services.
- Care leavers who moved to new areas were sometimes unsure about how to register with a GP and felt uneasy about contact with a new GP.
- Young people often had limited understanding of their mental health condition and the importance of taking prescribed medication consistently.
- There were concerns about barriers to accessing CAMHS and AMHS for those without a clear diagnosis, particularly given the reluctance from CAMHS to diagnose mental illness.
- There were waiting lists and delays for access to both CAMHS and AMHS and a shortage of in-patient care for young people in NI.
- There was also a gap in provision for care leavers with substance misuse issues and mental health needs as AMHS often refused services for these young people.
- Young people were often discharged early from AMHS for failing to attend clinical appointments.
- Social workers were frustrated that they could not refer directly to AMHS, highlighting the professional hierarchy within mental health services, and indicating that a stronger multi-disciplinary approach to supporting care leavers is needed.
- In Trusts where CAMHS were physically co-located with 16+ teams, close working relationships had developed across both services.
- Those who had co-existing intellectual disabilities had to rely on learning disability psychiatric services to meet their care-related therapeutic needs met. In contrast, young people with ASD who had mental health needs were directed by 16+ teams to CAMHS.
- Young people gave mixed accounts of CAMHS, with some feeling very poorly served and others very positive about the benefits of the intensive support and therapeutic interventions they received. CAMHS worked more flexibly than AMHS at the young person's level and pace, often in partnership with 16+ teams and occasionally beyond the age of 18.
- Young people noted a major change in service culture when they transitioned to AMHS with a more rigid, clinical and time limited focus on medication and/or diagnosis.
- Many young people struggled to adapt to the AMHS approach and disengaged, including those with severe mental ill health or presenting with ongoing risk of self-harm or suicide.
- A more flexible approach to mental health services that accounts for the unique needs of care leavers and adopts a more therapeutic approach up to the age of 25 is needed.

### 4.5.4 Youth Justice Services

A total of 12 of the 31 young people had prior involvement with the youth justice system, with three young people having extensive criminal records. Criminal activity ranged from more minor offences to more serious crime, such as, grievous bodily harm. Young people who had lived in children's homes were more likely to have a criminal record than those living in family-based care:

*In your own home if you flipped the bap and punch something and break something that's alright... You get grounded or something. But if you're in a home you're lifted [arrested] for it... in all my criminal charges there is maybe one or two just my own with my mates but the rest of them*

*are being arrested in the children's home for doing something stupid. All my convictions were in the period when I was in care so I only had a youth record and nothing after 18 (Jake).*

However, involvement with the police and justice sector could also threaten those family-based care placements as carers struggled to cope with anti-social or criminal behaviour.

Spending time in prison or on youth justice programmes provided support for young people to address wider needs linked to offending behaviours such as substance misuse issues and to learn more positive behaviours:

*Prison also opens your eyes and makes you realise. So with that reality check and wanting to get off drugs myself it was easy enough to stop (Diane).*

Some young people revealed that their criminal activity was a deliberate attempt to remove themselves from risk in the community, including threats from paramilitary groups, and negative peer groups and gave them an opportunity to change the direction of their lives:

*I didn't really mind going up to the juvenile place anyhow... I got out to clear my head really for a few months. I would have been involved quite heavily with paramilitaries... I wanted to leave all that... I could have got shot... so I thought the best option was just get arrested. I realised I had to wise up for my own sake... I just got my head cleared and... That's when I turned around then... not getting in trouble with the police or running around with the same crowds (Jake).*

Young people sometimes had an ambivalent attitude towards criminal behaviour and the consequences of their actions. Some young people were actively engaged in support to reduce offending and benefited from a flexible approach from youth justice services, however, leniency from the police or youth justice sector was not always being in their best interests.

Social workers shared concerns about how well disability or mental health related needs were being met within the prison system. Some social workers indicated that young people with mental health needs and intellectual disabilities had drifted into criminal activity due to unmet support needs. When care leavers were on bail or discharged from prison there were also difficulties with securing safe placements for them in the community.

It should be noted that, due to the small numbers of young people who had experienced youth justice services and, given that only a few young people discussed their involvement in the system, our data on this issue is limited. However, the initial findings reported here indicate that this is an important topic for future research.

#### **SUMMARY**

- A third of the sample had a history of involvement with the criminal justice system at some point mainly whilst they were in care, especially those in children's residential homes.
- A number of young people availed of programmes aimed at reducing their offending behaviours and found them helpful. Support for young people to understand the severity and consequences of criminal behaviour was highlighted.
- Social workers indicated a need for better understanding of disability and mental health in the criminal justice system and as young people were discharged back into the community.



#### 4.5.5 Cross-Sector Working

There were some examples of effective cross-sector working on particular cases, particularly more complex cases involving a wide range of agencies. However, these examples were often focused on complex cases and depended sometimes on relationships between individual professionals.

The major barriers to cross-sector working were separate policies which created service gaps and resource constraints as individual teams protected their own caseloads and budgets:

*The whole transition process is... difficult... There are so many different people with different criteria, with different policies and different services and now with tightening budgets those doors are all tightening closer and closer. Sometimes you can find you're bouncing from one door to another... 'It's not ours and it's not ours' but you know they're falling between stools and you can find it extremely frustrating because services are getting tighter and it's getting more and more difficult (Simon's social worker).*

Social workers, therefore, emphasised the need for closer working relationships between child and adult services and with 16+ teams and improved systems for transfer of cases to adult services. There was a consistent theme from interviews with 16+ social workers that care leavers need greater prioritisation in other services as all statutory services have corporate parenting responsibility for meeting their needs. Indeed, legal knowledge of the entitlement of care leavers was often used by 16+ teams to leverage support from other agencies. There was particular concern about the reliance on 16+ teams to solely meet the full range of care leavers with mental health and/or intellectual disabilities as these young people were left in a vulnerable position in the community with no alternative support when their cases closed at 21 if they were not engaged in employment, education or training.

The point of transition planning was a key opportunity for the range of services to work together on a plan for a care leaver's transition to adult life. Whilst a range of disciplines often worked well together within disability or mental health teams, there was a lack of such collaboration across teams. An integrated transition policy could support more effective collaborative working, however, such a policy needs to be inclusive of child and adult disability and mental health services and 16+ services.

Indeed, with further investment and collaborative efforts, the role of transition co-ordinators in children's disability teams who work with disabled young people in transition from school (age 14-25) could be a more useful source of additional transition support for 16+ teams working with disabled care leavers.

Overall, there was a need for clearer pathways for care leavers across child to adult services and provision for those with borderline disabilities/lower level mental health needs and ASD who do not meet the threshold for adult services and often fall between service gaps. Whilst social workers in 16+ services were often pushing the boundaries of their role in an effort to support young people, the lack of flexibility from adult services was frustrating. Many social workers indicated that adult services needed to have a better understanding of the circumstances of care leavers to respond appropriately to their needs and fulfil the shared responsibility of corporate parenting:

*We need a presumption for vulnerability for care leavers... A corporate parenting policy for the Trust... and getting other government departments to recognise that they too are corporate parents and as such can that presumption of vulnerability be extended through all government departments... So rather than looking to keep them out of the system... there needs to be an extension... Much more of an approach towards young people (Charlie's social worker).*

## SUMMARY

- Delays in assessment and challenges related to accessing specialist disability and mental health services, particularly as young people moved from child to adult services, often resulted in a reliance on 16+ teams to meet the needs of care leavers with mental health and/or intellectual disabilities.
- There is a need to highlight the corporate parenting responsibilities of all staff and services with regard to meeting the needs of these care leavers.
- Clearer pathways from child to adult services are needed alongside closer collaborative arrangements across service sectors for the full range of care leavers, including those with borderline or lower levels of impairment who do not meet the threshold for adult services and fall between service gaps.
- The main barriers to cross-sector working were resource constraints and separate policies which created service gaps.
- Closer collaboration offers the opportunity for more effective use of existing resources, a shared knowledge and skill base and more integrated transition supports.
- Overall, there is also a need for clear cross-sector pathways onwards from 16+ teams, particularly when cases closed at 21 for those perceived to have ongoing needs but no access to alternative supports.

### 4.5.6 Staff Training

As the study found limited evidence of close multi-disciplinary working across child and adult sectors, it was important to consider the training offered to teams leading on support for care leavers with mental health or intellectual disabilities.

The two main providers of support for care leavers from the age of 16-18 were children's disability or 16+ teams (those in contact with CAMHS were led by 16+ social workers). Social workers in children's disability teams accessed training related to disability issues, child protection and LAC procedures but had minimal training on issues for care leavers. Social workers in 16+ teams accessed training on: care leaver policy; issues affecting the lives of care leavers, such as, substance misuse; and general mental health issues. However, the extent of disability training for 16+ social workers was very limited:

*There's not so much learning disability training out there to be honest. That tends to come in around the disability awareness and... disability discrimination... I think the problem is things like autism awareness training when it's advertised gets filled because there's four, five, six times the number of spaces people applying. It's full ten times over (Lorna's social worker).*

Many 16+ social workers emphasised that there was an increasing prevalence of care leavers with autism on their caseloads yet they had great difficulty accessing any training on understanding the effects of autism or how to adapt their practice approach to work more effectively with care leavers with autism. Some social workers had undertaken personal study to add to their knowledge but had limited access to formal training:

*I don't think in my time in 16+ I have accessed any disability training... We don't have training in mental health and disability and the different aspects of those. We very much learn on the job*

*and independently try and research and find out what we can about conditions as they come up (Tina's social worker).*

Reflecting the issues relating to cross-sector working, social workers also indicated that joined up training involving all of the teams across child and adult services interfacing with care leavers would be helpful. Such training could help to bring professionals together from across sectors to enhance their understanding of each other's roles and responsibilities in relation to meeting the needs of care leavers and develop ideas on how to integrate services and utilise resources available more effectively across sectors.

Whilst these findings indicate areas where further training should be provided to staff in various teams, it is important to note that social workers also highlighted that time was often a barrier to their participation in training. Indeed 16+ staff recalled situations when they had to cancel participation in relevant training courses due to the demands of their work or unexpected crises in their case loads.

#### **SUMMARY**

- Staff in 16+ or children's disability teams who were leading on support for care leavers with mental health and/or intellectual disabilities struggled to gain access to specialist training, particularly on disability issues.
- Joint cross-sector training on roles and responsibilities related to care leavers is required to develop knowledge of care leaver issues across child and adult teams and to clarify how different service sectors could develop more collaborative practice approaches.
- Staff also need protected time to engage in training as their work is often unpredictable due to the demands of case related work in the context of limited staffing.

## **5.0 DISCUSSION AND RECOMMENDATIONS**

This is one of only a few studies worldwide to examine the particular needs and experiences of care leavers with mental health and/or intellectual disabilities and, therefore, makes an important contribution to our knowledge of these groups of care leavers. The findings are wide ranging, highlighting the diversity of experience within the population of care leavers with mental health and/or intellectual disabilities and the importance of access to both generic and specialist services to meet their transitional needs. Key factors associated with successful care leaving experiences were: consistent relationships with professionals who understood the issues impacting on the lives of care leavers with mental health and/or intellectual disabilities; early assessment and prompt access to specialist child and adult services; young people's participation in plans and decisions affecting their lives; and flexible collaborative practice across 16+, disability and mental health teams. Young people in the study sample who were high level service users usually had more severe or multiple mental health and/or intellectual disabilities and were often deemed to require lifelong support. Lower level service users tended to be those with mental health needs or borderline impairments who were excluded from services because they did not meet the eligibility criteria or who had disengaged from services. Due to lack of access or uptake of preventive support services, these young people were likely to enter other service systems as young adults including services for those who are homeless, engaged in criminal behaviour and/or substance misuse. The study, therefore, highlights the importance of building connections with a combination of informal community-based supports and formal, specialist services for care leavers with mental health and/or intellectual disabilities – a whole person/whole system approach. The findings also provide clear indications of policy and practice approaches that work well and those that need improvement.

### **5.1 WHAT WORKS WELL?**

There were many examples in care leaver accounts of approaches to practice that worked well and assisted care leavers to make a smoother transition and to move towards reaching their full potential. The following seven core features of effective practice emerged from the data.

#### **5.1.1 Commitment to Supporting Care Leavers**

Some care leavers benefitted from contact with professionals across 16+, disability and mental health services who had gone above and beyond their expected duties to support them as they transitioned from child to adult services. These young people had intensive and flexible support when they most needed it, often outside usual working hours, and had developed close working relationships with professionals who clearly demonstrated their commitment to the wellbeing of care leavers. Professionals who had the most effective relationships with young people understood why care leavers tested their relationship and worked at their pace, demonstrating a sense of 'never giving up' on the young person. This level of effort and commitment was greatly valued by young people who felt it demonstrated genuine care for them.

#### **5.1.2 Sixteen+ Service Culture**

Many of the staff in 16+ teams had a wealth of experience of working directly with young people and demonstrated a sound understanding of their needs and behaviours and how best to support them.

There were numerous examples of 16+ social workers and PAs working closely with young people, persisting with efforts to connect with disengaged young people and stretching the traditional boundaries of their role to support young people whenever they most needed it, including out of hours support. Staff in 16+ teams had also developed effective partnerships with other agencies, such as, those providing accommodation and education which greatly assisted their work.

### **5.1.3 Specialist Adult Service Provision**

In most cases, there were delays with access to assessment and services from adult disability and mental health services however, once secured, these were specialist services meeting the ongoing needs of care leavers with mental health and/or intellectual disabilities as they moved into adult life. In some Trusts, transition coordinators played an important role for disabled young people moving on from children's disability services. They coordinated services during the transition phase, undertook person-centred planning and assisted with referrals to adult services.

### **5.1.4 Co-locating Services**

Staff who worked in 16+ teams who were co-located with mental health or disability services tended to have closer working relationships. These 16+ staff were able to engage in informal consultations with specialist colleagues for advice on alternative approaches or additional support. These informal working relationships also facilitated better formal multi-disciplinary working as teams knew each other well, understood each other's roles and respected their specialist areas of knowledge.

### **5.1.5 Flexibility**

Young people and professionals repeatedly emphasised that working with care leavers demands a flexible approach that often does not fit well with rigid service structures or procedures. There were many cases where greater flexibility was needed, however, there were also some examples of professionals who worked creatively to facilitate ongoing support for young people who would otherwise have missed out on services. Examples included: 16+ staff successfully advocating for the age limit of 21 not to be rigidly applied to young people returning to education just beyond the age which allowed for financial support; CAMHS continuing to provide care for a young person who had turned 18 due to an ongoing crisis or to finish a programme of therapy; and clinic based practitioners providing home visits for young people who were unable to attend appointments due to the nature of their ongoing mental health needs.

### **5.1.6 Former Carer Support**

Young people who were leaving longer-term foster care or kinship care placements often had access to ongoing informal support that led to better outcomes as they transitioned into adult life. In some cases, these carers continued in their role under the GEM scheme after young people turned 18. In other cases, young people moved into independent or supported living, however, former carers continued to support them on a very regular basis. For example, carers regularly visited young people in their new homes, invited them back to their foster home for meals or assisted with their laundry or grocery shopping. These carers were also key in identifying any early deterioration in young people's

mental health and taking action to prevent further breakdown and to support their recovery. In such cases, it could be possible for former carers to become Person Specific PAs. These roles need to be carefully agreed with care leavers who were keen to reduce ongoing involvement of former carers who were over-protective. In addition, intensive supported accommodation and supported lodging schemes where young people were accommodated by carers to live independently in their home worked very well but a limited range of these placements were available across NI.

### **5.1.7 Participation in Post-care Decisions**

Whilst there were indications that participation levels were low for LAC and improvements to pathway planning processes were recommended, generally care leavers over 18 played an active role in decisions about their post-care lives. Young people with more severe impairments experienced lower levels of participation, however, there was evidence of some 16+ social workers seeking alternative methods for engaging these care leavers in decisions and care plans. For example, using more informal methods of non-direct communication or adapting pathway planning documents to make them more accessible to young people with a range of communication needs.

## **5.2 WHAT NEEDS TO BE IMPROVED?**

The findings from this study indicate clear areas where policies and services need improvement across generic leaving care services and specialist mental health and disability services. Key areas for improvement include better identification and monitoring of disability amongst the care leaver population; earlier intervention; and clearer pathways to specialist services. Corporate parenting responsibilities are also emphasised, alongside a focus on relationship-based practice. In addition, the findings highlight broader areas of care leaver experiences that indicate a need for a wider focus on ending discriminatory societal attitudes towards care leavers, disability and mental health.

The four overarching areas for improving policy and practice for care leavers with mental health and/or intellectual disabilities are outlined in the quadrants for change in figure 1 and discussed in more detail below.

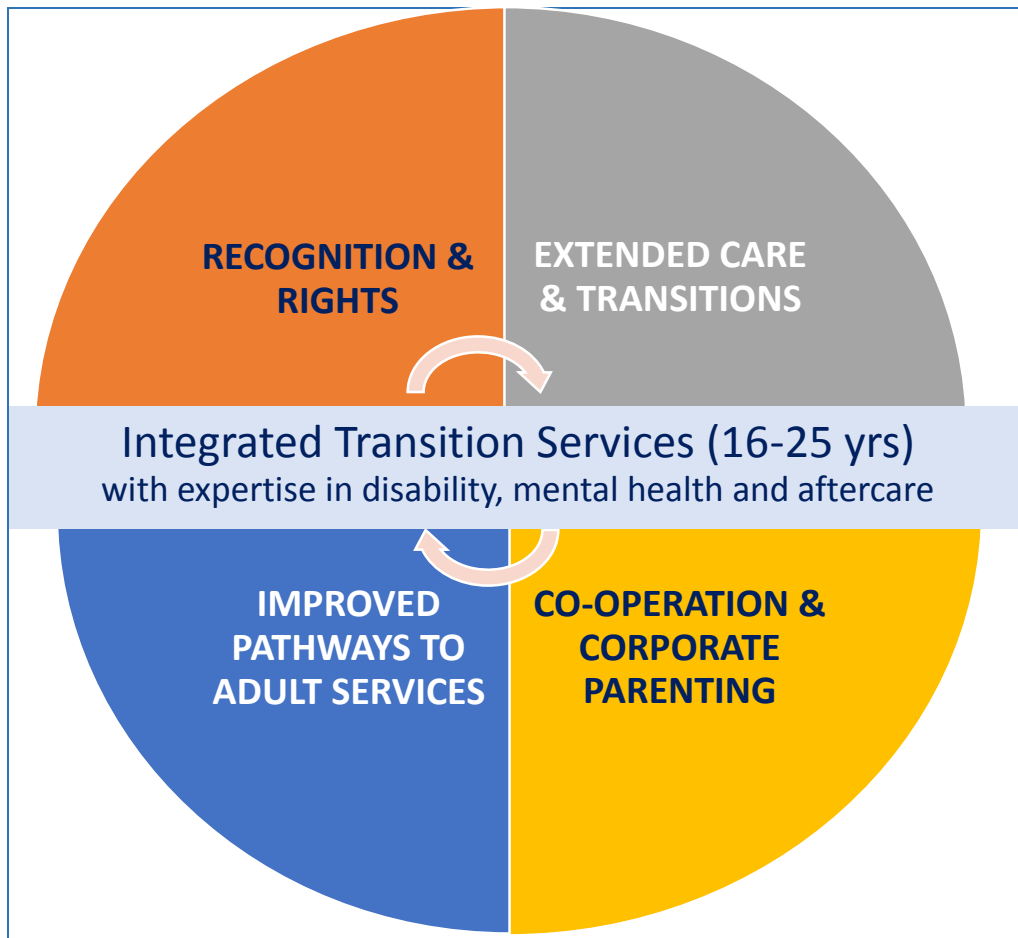


Figure 1: Quadrants for Change.

### 5.2.1 Recognition and Rights

A persistent theme in the study findings is the need for clearer recognition of care leavers with mental health and/or intellectual disabilities in policy documents, statistical returns and practice initiatives. These young people need to be recognised as two sub-groups within the care leaver population who have particular experiences of leaving care and post-care outcomes (sometimes overlapping, given the prevalence of multiple impairments). Without explicit attention to these sub-groups of care leavers, their over-representation in the care leaver population and their specific needs are at risk of being ignored. There is also a need to better understand the different trends in the prevalence of impairment types in the care leaver population across Trusts. It is important, therefore, to improve methods and systems for identifying, collating and maintaining records of impairment type within the care leaver population at a regional level. These data collection systems should produce more accurate information on separate impairment categories (for example, separating ADD/ADHD from the ASD category) and account for co-existing impairments. Developing a comprehensive database on the care leaver population that accurately records impairment types would help to develop our knowledge of this population over time, inform service development to more effectively meet their needs as they transition from care and facilitate comparative analysis of needs and outcomes of care leavers with and without mental health and/or disabilities.

Assessments of mental health and disability related needs should be undertaken when children come into the care system to facilitate earlier diagnosis and identification of their need for specialist support, to inform decisions about the most appropriate care placement and services to meet their needs and to monitor the effectiveness of provision in meeting the assessed needs. Further recognition of the needs of care leavers with mental health and/or intellectual disabilities also helps to ensure that staff and carers are well trained and supported to provide a suitable care environment and approach and reduces the risk of placement breakdown which is a common experience of young people with mental health and/or intellectual disabilities. In preparation for leaving care, young people should also have access to early re-assessment of mental health and disability related needs to facilitate timely transition planning and access to adult services. As the survey found that care leavers with mental health needs were more likely to access 16+ services than those with other impairment types, despite similar care leaver status, there is a need for further recognition of the responsibilities of 16+ services for all disabled care leavers. Some study participants also had low levels of contact with Pas. This requires further attention, particularly in Trusts where there is a growing reliance on PA services to support young people who have left care. In addition, the numbers of care leavers with mental health and/or intellectual disabilities who are parents reflect the same trends for the wider leaving care population, highlighting the need to recognise the prevalence of mental health and disability within the population of care leavers in NI and to provide accessible and disability aware educational programmes about sexual and personal relationships and effective parenting.

There are also areas of improvement required for care leavers in general that would also benefit care leavers with mental health and/or intellectual disabilities if they were specifically recognised in new policy and practice initiatives. For example, revision of pathway planning documentation to make it less patronising and more age appropriate would benefit all care leavers. However, diversifying the approach to pathway planning through use of technology and less formal planning processes would be particularly useful for care leavers with mental health and/or intellectual disabilities who require alternative and more person-centred approaches to engagement and communication. Similarly, many care leavers experience financial hardship and fear loss of limited income from housing or unemployment benefits. However, these concerns were particularly relevant to care leavers with mental health and/or intellectual disabilities who found it difficult to navigate the complex benefit system or who became more dependent on disability related benefits which served as a disincentive to engaging in further education or full-time work. These findings shift the focus from individual financial struggles to wider systemic failings that can lead care leavers with mental health and/or intellectual disabilities to become dependent on welfare benefits and at risk of high levels of debt and poverty. Care leavers with mental health and/or intellectual disabilities also have limited access to befrienders and independent advocates. These are core services that should target care leavers with mental health and/or intellectual disabilities who are missing out on these essential services.

A recurring theme in the study findings is the importance of consistent professional relationships with care leavers and access to a worker who genuinely cares. Such relationships are important for any care leaver, however, they are particularly crucial for those with mental health and/or intellectual disabilities who engaged more effectively with services offering a stable routine and familiarity. Professionals indicated that low uptake of services was sometimes due to the young person's disengagement. However, when the young people felt understood and when professionals demonstrated their ongoing interest in their lives and care for their wellbeing, they often re-engaged with services and greatly valued the close relationship with their worker. Effective practitioners were also strengths-based, focusing on the capacity, not only the challenges, of being care leavers with mental health and/or intellectual disabilities. These workers supported the young people's positive aspirations for their futures in a way that enabled them to realise their full potential.



Finally, the findings indicate that care leavers with mental health and/or intellectual disabilities experienced discrimination and stigma on the multiple grounds of their care leaver status, disability and mental health. Study participants experienced bullying, intimidation and abuse in personal relationships, schools/colleges and their neighbourhoods which was rarely adequately addressed by public services. Such discriminatory treatment negatively affected their self-esteem which led to socially isolated lives and restricted opportunities for education, training or employment. Discriminatory treatment also encouraged some young people to deliberately conceal their identities and withdraw from specialist services in order to disassociate from imposed labels as a care leaver or person with mental illness or disabilities. There is a need to raise awareness of the rights of these young people to be protected from discrimination, alongside the provision of more effective therapeutic support to develop positive self-identities that counteract negative stereotypes. Finally, the inclusion of care leavers with mental health and/or intellectual disabilities in their local communities, drawing on their interests and talents and building their inter-connected community networks would help to promote positive peer relations and protective social relationships.

#### **Recommendations for Policy and Practice:**

1. Systems for identifying and collating records of impairment type within the care leaver population must be improved to ensure a consistent, accurate approach to recording and monitoring the population of disabled care leavers across Trusts in statutory data returns.
2. Children should have an assessment of health and disability related needs on entry to care to facilitate diagnosis, timely access to specialist support and allocation to appropriate care placements. Staff and carers should also have specialist training and support to meet the diverse needs of these children. As young people prepare to leave care, early re-assessment of health and disability related needs should be undertaken to facilitate timely planning and referral to adult services. Pathway planning approaches should utilise more creative, person-centred ways of engaging young people with mental health and/or intellectual disabilities.
3. The prevalence of mental health and/or intellectual disability within the population of parenting care leavers highlights the need to develop accessible and disability aware educational programmes about sexual and personal relationships and effective parenting.
4. Access to 16+ services for care leavers with intellectual disabilities and/or ASD should be reviewed to ensure they have equal access to the full range of leaving care services they are entitled to. Future commissioning of mentoring and independent advocacy services should target care leavers with an intellectual disability and/or ASD who have very limited access such services. Levels of contact with PAs should be reviewed to ensure all efforts are being made to encourage engagement and offer alternative support options.
5. A review of welfare benefit usage and self-directed support opportunities for care leavers would help to elucidate some of the barriers to financial support and develop ideas on how best to economically support care leavers with mental health and/or intellectual disabilities and encourage their engagement in education, training or employment.
6. Professional and public education is required to raise awareness of the legal rights of care leavers with mental health and/or intellectual disabilities to be protected from discrimination and to develop strategies for effective redress and therapeutic support for those who have experienced discrimination.
7. Professionals must also be supported to develop their practice methods and skills in providing person centred, relationship based practice with care leavers with mental health and/or intellectual disabilities that adopts a strengths-based perspective. This requires the retention of trained staff and structures that allow for stable relationships over time between key front line staff and care leavers.
8. Community development approaches that facilitate the inclusion of these care leavers in local communities should be used to build community connectedness and expand their access to protective, enriching social relationships.

### 5.2.2 Improved Pathways to Adult Services

Across Trusts there was a lack of clarity about pathways from child to adult service provision across the domains of 16+, disability and mental health services. Eligibility criteria for access to specialist mental health or disability services based on a strict adherence to severity of impairment fails to address the ongoing needs of care leavers with mental health and/or intellectual disabilities. Staff in 16+ teams also have limited access to specialist mental health and disability services for information, advice and assessment.

In addition, the study found a lack of suitable supported housing or adult residential placements for care leavers with mental health and/or intellectual disabilities, with many social workers struggling to identify supported accommodation for these care leavers. Supported accommodation worked well for some young people, particularly where more intensive support was required and provided. However, these were often short-term placements with a view to moving into independent living and limited availability whereas longer placements were required. In addition, gaps in the provision of in-patient psychiatric care for young people have been reported by young people and social workers.

There are also particular sub-groups of care leavers who are falling between service gaps including care leavers with: ASD, borderline levels of impairment and those engaged in substance misuse. These young people found it difficult to access specialist services indicating a need to develop services tailored to meet their specific needs or to widen the remit of existing disability and mental health services to be more inclusive of these young people. There are also geographical variations in the availability of services for care leavers across the province with young people and professionals indicating that those in more rural areas are disadvantaged by urban services which are targeted at those living in cities.

The findings of the study also show the important role played by the voluntary sector which requires continued investment, particularly in relation to peer support and assisting care leavers with housing, finances and education or employment training. However, care leaver organisations need to have a greater understanding of disability and mental health issues and organisations focused on disability or mental health need to build up their awareness of care leaver issues.

#### **Recommendations for Policy and Practice:**

9. Clear regionally agreed transitional pathways from 16+ and child to adult disability and mental health services are required to ensure needs and entitlements are fully met.
10. Eligibility criteria for access to specialist mental health or disability services should be clear and not solely based on a strict adherence to severity of impairment for care leavers with mental health needs and/or intellectual disabilities. Staff in 16+ teams should also have pathways of communication with specialist mental health and disability services so they can access information, advice and assessment without delay, if required, including support to make greater use of self-directed individualised packages of support.
11. Services should be developed to meet the needs of young people with ASD, borderline levels of intellectual disability and those engaged in substance misuse; or existing disability and mental health services should be extended to include these young people within their remit.
12. A review of post-care provision for care leavers with mental health and/or intellectual disabilities (including those in rural communities) should be undertaken to identify and address gaps in provision and areas for service development. In particular, further supported accommodation options allowing longer stays and in-patient care for care leavers with mental health and/or intellectual disabilities are required.

### 5.2.3 Extended Care

Young people leaving residential care were disadvantaged by the requirement to leave children's homes at 18 compared with those who had a more phased transition from foster care or remained in foster care under the GEM scheme. Care leavers with mental health and/or intellectual disabilities leaving residential care had more limited informal sources of support and opportunity to practise skills for independent living whilst they were still in care and, as a result, often struggled to cope with the demands of independent living.

The study also found that there is a withdrawal of leaving care services as young people age out of children's services at 18. This withdrawal of leaving care services may be appropriate for young people moving on to more independent post-care lives, however, there is concern among social workers that care leavers with mental health and/or intellectual disabilities have unmet needs as they exit 16+ services and require more extended support. Under current policy, care leavers who are not in education, employment or training (NEET) who reach the age of 21 are no longer eligible for 16+ services. This policy disadvantages care leavers with mental health and/or intellectual disabilities who have ongoing support needs post-21 but are not in a position to engage in education, employment or training for a range of reasons including mental ill health, parenting responsibilities or crises related to family circumstances or housing. In addition, care leavers with borderline or mild levels of intellectual disability were often not eligible for adult disability services and were reliant on 16+ teams to meet their ongoing support needs. Staff in 16+ teams expressed much concern for these care leavers when access to 16+ services ceased at 21. Raising the age at which young people cease to be supported by 16+ services was strongly recommended by young people, birth parents and carers as care leavers are vulnerable to poor outcomes in all areas of life well into their twenties.

Similarly, CAMHS cease when care leavers reach 18, however, these services could be extended to 21 or 25 for care leavers who require ongoing therapeutic intervention from trusted mental health professionals who understand their care histories rather than experiencing an abrupt transition to AMHS which have a more time-limited, clinical approach focused on diagnosis and treatment. It is also important that GPs and AMHS professionals have a sound understanding of the specific needs of care leavers and offer a greater range of accessible, therapeutic support for these young people.

#### **Recommendations for Policy and Practice:**

13. Young people with mental health and/or intellectual disabilities leaving residential care should have access to more stepped approaches to transition to enable them to develop skills for independent living.
14. There is a need to extend 16+ services for care leavers with mental health and/or intellectual disabilities who require post 18 support as they experience further change and transition well into their twenties. In particular, care leavers with borderline levels of impairment should have access to ongoing support from either 16+ teams or specialist disability/mental health teams.
15. CAMHS could be extended to 21 or 25 for care leavers who require ongoing therapeutic intervention from trusted mental health professionals with whom they are already working closely with rather than an abrupt transition to adult mental health services which has a more clinical approach.
16. The current policy on the cessation of 16+ services for care leavers who are NEET disadvantages those with mental health and/or intellectual disabilities who have ongoing support needs post-21 and are not in a position to engage in education, employment or training. When the cases of these care leavers are due to close at 21, they should be carefully reviewed and a needs assessment should be undertaken and, if required, responded to with the provision of ongoing support from 16+ or adult service providers.

#### 5.2.4 Co-operation and Corporate Parenting

There is a clear message in the study findings that care leavers with mental health and/or intellectual disabilities need to be recognised by mainstream and specialist services as young people for whom the Health and Social Care Trust has ongoing corporate parenting responsibilities, rather than such duties being viewed as the sole responsibility of LAC or 16+ teams. This places an onus on child and adult disability and mental health services to respond more proactively to the needs of these care leavers. It is essential, therefore, that adult services widen their eligibility criteria beyond impairment/diagnoses to allow for the assessment of the needs of care leavers with mental health and/or intellectual disabilities and the provision of services to meet these identified needs in recognition of their unique circumstances and the Trust's corporate parenting responsibilities.

The study findings also highlight the need to share knowledge and expertise across specialisms and facilitate more creative forms of collaborative working. For example, staff in 16+ teams are very keen to develop their skills for working directly with care leavers with intellectual disabilities/ASD but they had very limited access to relevant training or opportunities to liaise with specialists in disability or mental health services. Likewise, professionals in child or adult disability teams had limited knowledge of care leaver experiences or service entitlements. The development of person-centred services for care leavers with mental health and/or intellectual disabilities requires more effective linkages between 16+ services, transition services in schools/disability services and adult services to avoid crisis driven transitions and abrupt moves to adult care placements. Within Trusts and at a regional level, efforts must, therefore, be made to bring professionals together across service boundaries and provide more integrated practice for these care leavers.

As young people with mental health and/or intellectual disabilities left care, they also engaged with a range of public agencies with responsibility for education, employment and learning, housing, public health, social security, leisure, youth justice and policing. Lead agencies need to take responsibility for engaging with partner agencies to fulfil corporate parenting duties through the establishment of joint protocols and regular strategic and operational meetings to facilitate effective working relationships based on continuous collaboration. Raising awareness of the needs of care leavers with mental health and/or intellectual disabilities across service systems and training for staff at all levels within organisations should help to improve co-operation from the full range of public agencies. Indeed, the Children's Services Co-operation Act NI 2015 provides an obligation for public agencies to collaborate more effectively in the interests of children and young people, including care leavers with mental health and/or intellectual disabilities.

##### **Recommendations for Policy and Practice:**

17. A clear, regional transition policy for care leavers with mental health and/or intellectual disabilities setting out unambiguous roles and responsibilities is required.
18. Adult services must assess the needs of care leavers with mental health and/or intellectual disabilities, rather than a sole focus on impairment level/diagnosis, to ensure they fulfil their corporate parenting duties for care leavers over 18.
19. Trusts must establish protocols and mechanisms for more effective collaboration across services to avoid crisis driven transitions, duplication of roles and delays in access to essential services for care leavers with mental health and/or intellectual disabilities. Joint training across 16+, mental health and disability teams would help to develop understanding of roles and responsibilities and to facilitate collaboration. Reflecting Personal and Public Involvement (PPI) duties (DHSSPSNI, 2012d), care leavers with mental health and/or intellectual disabilities should be involved in the delivery of such training initiatives.

### 5.2.5 Integrated Transition Services

Many of the challenges for young people and social workers in 16+ teams were related to barriers to accessing the required range of services to meet the multiple and diverse needs of care leavers with mental health and/or intellectual disabilities. The persistent lack of access to consistent and specialist support for these young people as they transition from care is often due to the tendency for services to work in silos with a narrow focus on their particular specialism or service categorisation. Rigidly compartmentalising services in this way helps to manage budgets and caseloads in the context of service cutbacks, however, it is restrictive for care leavers with mental health needs and/or intellectual disabilities who have co-existing needs who require access to more than one specialist service.

With the renewed focus of the Children's Services Co-operation Act NI 2015, there is an obligation for more collaborative assessments of need and integrated services. Under this legislation, there is an opportunity to explore more innovative ways to share and combine services, co-locate staff and pool funds in the interests of care leavers with mental health and/or intellectual disabilities. The findings of this study suggest that integrated policies and procedures focused on care leavers with mental health and/or intellectual disabilities would assist collaboration across teams. It is, therefore, recommended that an integrated transition service for care leavers mental health and/or intellectual disabilities aged 16-25 years should be developed and piloted in at least one Trust area, with a view to scaling up to a regional service. This service would be staffed by co-located, multi-disciplinary professionals with specialist expertise in disability, mental health and aftercare who work together to ensure consistent, person-centred support that gives full recognition to the wide ranging needs of these care leavers. This service should also aim to promote greater use of direct payments and individualised funding packages for care leavers with mental health and/or intellectual disabilities.

The development of an Integrated Transition Service would reduce the need for a wholesale extension of 16+ services or CAMHS to meet the needs of these care leavers and also ease pressure on adult disability and mental health services to provide services for this group until they are in their mid-twenties and have had an opportunity to settle into their post-care lives. This new transition service, however, needs to be adequately resourced and supported by management and requires active co-operation from other public agencies. The service also needs to be carefully evaluated to measure the outcomes for young people using and exiting the service.

#### **Recommendation for Policy and Practice:**

20. A new Integrated Transition Service for care leavers with mental health and/or intellectual disabilities aged 16-25 should be piloted and evaluated in at least one Trust area, with a view to scaling up to a regional service. This service would be staffed by co-located multi-disciplinary professionals with specialist expertise in disability, mental health and aftercare and guided by a clear transition policy grounded in a firm commitment to collaboration and person-centred practice. In accordance with PPI responsibilities, care leavers with mental health and/or intellectual disabilities should be actively involved in the development and evaluation of this service.

### 5.3 IMPLICATIONS FOR FUTURE RESEARCH

This study provides new insights into transitions and outcomes for care leavers with mental health and/or intellectual disabilities. However, the study findings also provide direction on areas for future research on this topic. The following five main areas should be prioritised for further research:

1. There is a need for comparative research that allows for identification of differences in experience and outcomes for care leavers with/without mental health needs and with/without disabilities. Our earlier recommendation on enhancing the accuracy of the record of disability and mental health in regional statistical returns on care leavers may help to differentiate between these groups of care leavers and provide a comparative sample for future research.
2. The study found examples of best practice including: relationship-based practice, flexible and creative approaches to engaging with care leavers, and ongoing support from former foster carers. There is a need for more detailed accounts and testing of such effective interventions to provide the basis for training and service development.
3. As this study focused on care leavers with mental health and/or intellectual disabilities, future studies on the experiences of disabled care leavers should aim to capture the views of young people with physical and/or sensory impairments. In addition, future studies with disabled care leavers should incorporate additional funding and time to ascertain the views and experiences of care leavers with multiple and profound levels of impairment who require use of alternative, participatory research methods.
4. Examining disabled care leavers' experiences of the criminal justice system was not a core aim of the study, however, our initial findings on this issue suggest that this is an important topic for future research.
5. This study has established a database of care leavers with mental health and/or intellectual disabilities that could facilitate further follow up research on their longer-term outcomes in adult life.

## **6.0 Conclusion**

Overall, this study addresses the important, yet overlooked, issue of transitions and outcomes for care leavers with mental health and/or intellectual disabilities in NI. The study began with a review of relevant policy and literature which set the scene for a survey profiling the population of care leavers with mental health and/or intellectual disabilities in NI and qualitative case studies providing rich data on the views and experiences of a sample of these young people.

The review of policy and literature showed a notable lack of attention to the experiences of disabled care leavers in both research and policy. Disability and mental health policies often acknowledge the challenges of transition from child to adult services more generally, but mostly fail to consider the needs of care leavers or young people with co-existing impairments who cross service boundaries. Similarly, with only a few exceptions, care leaver policies address the broader needs of care leavers as a homogenous group without taking full account of the needs of the substantial group of young people with mental health and/or intellectual disabilities who are leaving care. Similar trends can be observed in the research literature on leaving care. The review of literature indicated a clear need for further empirical research on the experiences of care leavers with mental health and/or intellectual disabilities to build knowledge of their specific needs and experiences. This study, therefore, makes an important contribution to knowledge of the needs and experiences of this particular group of young people. In addition to building a profile of this population of care leavers in NI, the case study approach incorporating a peer research methodology provides unique insight into the views of care leavers with mental health and/or intellectual disabilities and also the perspectives of their carers, birth parents, PAs and social workers.

The study found examples of best practice including: relationship-based practice, flexible and creative approaches to engaging with care leavers and ongoing support from former foster carers. However, there are also clear areas for service improvement to enhance support for care leavers with mental health and/or intellectual disabilities and to ensure full implementation of corporate parenting and co-operation duties under current law. The onus is on service planners, commissioners and providers to improve cross-sector working and implement integrated policies and practices to more effectively address the holistic needs of our care leaver population. There is also a need to re-examine provision for particular groups of care leavers who are most vulnerable to exclusion from support services and vulnerability in the community, including those with no clear diagnosis, borderline impairments or ASD. Finally, there are deeper issues of structural and cultural oppression with the study population experiencing stigma and discrimination which must be challenged under rights-based law in NI.

In conclusion, this study provides a comprehensive overview of the needs and experiences of care leavers with mental health and/or intellectual disabilities in NI. The recommendations outlined in the previous section provide clear direction for the future development of policy, practice and research. We urge policy makers, commissioners and service providers to listen to the views of young people presented in this report and take action to fully implement the study's recommendations to ensure they are more effectively meeting the diverse and intersectional needs of care leavers.

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