



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

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

## **SHORT REPORT**

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## RESEARCH BRIEFING

**Why did we start?** Care leavers with mental health and/or intellectual disabilities are over-represented in the population of young people leaving care in Northern Ireland (NI) (DHSSPSNI, 2015a). However, there have been no previous studies on the characteristics or experiences of these care leavers as they transition from care. We carried out this study to address this gap in knowledge by investigating transitions and outcomes for care leavers with mental health and/or intellectual disabilities in NI.

**What did we do?** We conducted a profiling survey, completed by individual social workers, of all care leavers in Northern Ireland on 30<sup>th</sup> September 2013 who had a mental health need and/or disability. A total of 314 completed surveys were returned, comprising 23.4% of the total population of care leavers. Case studies of 31 of these care leavers with mental health and/or intellectual disabilities were then conducted to further explore their experiences of leaving care and transitioning from child to adult services. Case studies involving reading case files and interviewing young people, carers, birth parents and social workers.

**What did we find out?** Young people with mental health and/or intellectual disabilities are over-represented in the care leaver population in NI but are rarely acknowledged in policy documents or statistical returns.

- These care leavers have reduced opportunities to stay with former foster carers and those leaving residential care have abrupt moves from care at 18. Those with mental health needs are more likely to move to tenancy arrangements and those with intellectual disabilities are more likely to return home.
- Almost a third are Not in Education, Employment or Training (NEET) and only one in ten are employed. Many experience financial hardship and need support to manage finances and welfare benefits.
- 16+ services reduce at age 18 and cease at age 21 for those who are NEET. A fifth do not have contact with their personal adviser. Pathway planning approaches are often patronising or inaccessible; and very limited access to independent advocacy and direct payments is reported.
- There are low levels of engagement in child and adult mental health and disability services. Delays in assessment and strict eligibility criteria based on impairment/diagnosis restrict access to adult services. Young people find the clinical and time limited approach to the adult mental health services unhelpful.
- There are gaps in services for those with: ASD, borderline levels of impairment and/or or those engaged in substance misuse. There is also a shortage of long-term supported accommodation and in-patient care for care leavers with mental health and/or intellectual disabilities in NI.
- Care leavers with mental health and/or intellectual disabilities experience stigma and discrimination on the multiple grounds of their care leaver status, disability and mental health.

**What should be done now?** To improve services for these care leavers, we need:

- Explicit identification of care leavers with mental health and/or intellectual disabilities in policy and statutory data returns on the care leaver population.
- Early assessments of mental health and disability; more accessible, person-centred planning; and stepped approaches to transition from residential care.
- A review of welfare benefit usage and self-directed support opportunities for care leavers.
- Increased access to 16+ and advocacy services for care leavers with intellectual disabilities and/or ASD.
- Extended 16+ services and Child and Adolescent Mental Health Services to provide ongoing support.
- More services for care leavers with ASD, borderline impairments and substance misuse needs.
- More supported accommodation allowing longer stays and in-patient care for care leavers.
- Clear regionally agreed transition pathways from child to adult disability and/or mental health services.
- More effective collaboration across services, including integrated transition services for care leavers.
- Community development approaches to expand access to protective, enriching social relationships.
- Education to raise awareness of the rights of these care leavers to be protected from discrimination.

## 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 our 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 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 disability; 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 any 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.

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<sup>1</sup> 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'.

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

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 care leavers 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).

This report provides an executive summary of the aims, methods and key findings of the study. Readers should refer to the full reports on each stage of the study or the final report (Kelly et al., 2016) for further details. Each report is available on the following web link: <http://www.research.hscni.net/bamford-implementation-commissioned-call-portfolio>.

## **1.2 BACKGROUND TO THE STUDY**

The study began with a review of previous research on care leavers with mental health and/or intellectual disabilities and a review of the policy context.

### ***Previous Research***

There is a very limited evidence base in relation to disabled care leavers and studies that have been undertaken are predominantly qualitative and small-scale. The small body of research available found that 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 risk of homelessness and experience of abuse and exploitation after leaving care (Edwards, 2010; Fudge Shormans & Rooke, 2008; Goldblatt et al., 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). Major problems for disabled care leavers are inadequate transition planning, limited post-care options and uncoordinated aftercare support (Goldblatt et al., 2010; Mendes et al., 2013; NFCA, 2000; NSW Ombudsman Review, 2004; Rabiee et al., 2001).

There is a much a larger body of research on the mental health needs of care leavers which is generally large scale, quantitative and based in the United States. This research provides clear evidence that care leavers are at high risk of experiencing mental ill health (Cashmore & Paxman, 2007; Courtney et al., 2012; Dixon et al., 2006; Viner & Taylor, 2005; Vinnerljung et al., 2006). Furthermore, there is a reported mismatch of psychotropic medication use to address mental health needs involving over and under use by care leavers (Raghavan & McMillen, 2008).

These studies clearly indicate that care leavers with mental health and/or disabilities face additional challenges as they transition from care yet they find it difficult to access specialist services across child and adult programmes of care. Staying in care longer, experiencing strong social support networks, accessing education and employment opportunities and engaging in consistent relationships with staff are critical factors associated with successful transitions from care (Cashmore & Paxman, 2007; Daining & DePanfilis, 2007; Dixon et al., 2006; Fowler et al., 2011). Services most likely to promote emotional wellbeing are those which enhance life skills and opportunities for further education, training and employment (Daining & DePanfilis, 2007; Fowler et al., 2011). Well-timed, planned and coordinated transitions from child to adult mental health/disability services are also essential (Brown & Wilderson, 2010; Courtney & Dworsky, 2006;

Dixon et al., 2006; Fowler et al., 2011; Goldblatt et al., 2010; Lamont et al., 2009; Mendes et al., 2013; Mullen et al., 2006; Pecora et al., 2005; Vinnerljung et al., 2006).

### ***The Policy Context***

There are four key policy areas relevant to care leavers with mental health and/or intellectual disabilities: child care, mental health, intellectual disability and transition (Kelly et al., 2014a). These four domains of policy must also be considered in the context of broader rights-based policies including the *United Nations Conventions on the Rights of the Child (UNCRC) 1989* and the *Rights of Persons with Disabilities (UNCRPD) (2006)*; the *Human Rights Act (1998)* and the *Disability Discrimination (NI) Order (2006)* which seek to address discrimination on the grounds of disability and promote equal access to services.

The main policies relating to care leavers in NI are the *Children (NI) Order 1995*, the *Children's Homes Regulations (NI) 2005*, the *Children (Leaving Care) Act (NI) (2002)*, the *Children (Leaving Care) Regulations (NI) 2005* and the *Standards for Leaving Care Services in NI* (DHSSPSNI, 2012). These policies clearly define the legal status of care leavers and place duties on Health and Social Care Trusts (HSCTs) to: maintain contact with young people after leaving care; provide aftercare until age 21 or 24 if they are still in further education and training; appoint a Personal Adviser (PA); and develop a pathway plan. Whilst most child care policy documents fail to specifically consider disabled care leavers, two notable exceptions are: *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 *Good Practice Guidance on Transition Planning for Young People Leaving Care with a Disability* (WHSCT, 2010) which is only a Trust advisory document.

Since the end of 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* which places a duty on children's authorities to co-operate in the provision of children's services. This policy has potential to facilitate improved cross-sector working in children's services in NI and has particular relevance to care leavers with mental health and/or intellectual disabilities who are likely to require a range of services across sectors.

The *Bamford Review* has been a leading driver of intellectual disability and mental health policy in NI, aiming to improve the health and wellbeing of those with mental health needs or intellectual disabilities. However, the continued absence of care leavers in Bamford action plans suggests a lack of recognition for this group as a priority in disability and mental health policy (DHSSPSNI, 2012c).

At the time of the study, the main mental health statute in NI was the *Mental Health NI Order (1986)*. Towards the end of the study, the *Mental Capacity Act (NI) 2016* was introduced which combines mental capacity law and mental health law into a single framework. Mental health services are also guided by the: *Service Framework for Mental Health and Wellbeing* (DHSSPSNI, 2011a); the *Service Model for Child and Adolescent Mental Health Services (CAMHS) in NI* (DHSSPSNI, 2012b); and the *Regional Mental Health Care Pathway* (HSCB, 2014). These documents promote a stepped care model to ensure services are matched to need and emphasise prevention, early intervention, proactive recovery and a whole systems approach.

Intellectual disability and autism services are also guided by the *Learning Disability Service Framework* (DHSSPSNI, 2015) which emphasises co-ordinated services and transition planning for those leaving school; and the *Autism Act (NI) (2011)* which highlights the entitlements of people with

autism and the need for a collaborative service approach. In addition, the *Adult Safeguarding: Prevention to Protection in Partnership Policy* (DHSSPS, 2015b) addresses adult protection regardless of age or type of impairment. Young adults with mental health and/or intellectual disabilities are, therefore, included in this guidance. However, the policy does not specifically address young adults who are leaving state care and who may be particularly vulnerable.

Transitions for young people with intellectual disabilities and/or mental health needs are highlighted in a range of law, policy and planning documents such as, the *Disabled Persons (NI) Act (1989)* and the *Special Educational Needs and Disability (NI) Order (2005)*. However, much of the emphasis is on transitions from school rather than from public care (DENI, 2005; 2006).

Finally, 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 intellectual disabilities and their carers is low in NI.

Overall, the review of policy found that disability and mental health policy often fails to consider the needs of care leavers with mental health and/or intellectual disabilities. Likewise, disability and mental health issues are often not well-addressed within child care or leaving care policies. It could be assumed that universal policies for all young people/care leavers or all 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.

Based on the review of relevant policy and literature, it is clear that care leavers with mental health and/or intellectual disabilities are largely invisible in policy initiatives in NI and have been given limited attention in the body of research on leaving care. The current study seeks to address this gap in knowledge by investigating the profile of care leavers with mental health and/or intellectual disabilities in NI and their experiences of leaving care.

## 2.0 METHODOLOGY

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 Health and Social Care Board (HSCB) and in each Trust, in accordance with the Data Protection Act (1998).

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>3</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

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<sup>3</sup> This includes mild, moderate or severe levels of intellectual disability.

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 also included.

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).

## **2.1 SURVEY APPROACH**

A follow-up survey linked to the HSCB's bi-annual 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.

In order to facilitate the survey, the research team worked with the HSCB to amend the disability question 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.

With the amended disability question in place, the HSCB then asked each of the five HSCTs 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. Individual social workers were then asked to complete a profiling online survey for care leavers on their caseloads.

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.

## **2.2 CASE STUDY APPROACH**

The final stage of the study used qualitative methods to focus on the experiences and perspectives of care leavers with mental health and/or intellectual disabilities. As the study sought to explore the multiple experiences of young people from varying perspectives across the domains of youth leaving care, mental health and intellectual disability, a case study design was appropriate (Baxter & Jack, 2008; Yin, 2003). The case studies involved three main stages:

- Reading young people's social work case files to gather information about: care status; impairment; significant events, including placement changes; services used; engagement in education or employment; and post-care circumstances.
- Semi-structured interviews with each young person at up to three separate points over approximately 18 months as they transitioned from care.
  - Five young people who were care-experienced were trained as peer researchers to assist with these interviews. Further details of the recruitment, training and support provided to peer researchers are available in the evaluation report (Dowling, 2016).



- For young people with more severe intellectual disabilities, a shorter, pictorial version of the interview schedule was used incorporating use of feelings cards illustrating a range of emotions.
- Semi-structured interviews with social workers or PAs, and, where appropriate, their birth parent and current/former carer. With prior agreement, all interviews were audio recorded and transcribed for analysis.

The 31 case study participants were selected from the survey’s sampling frame 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.

Social workers helped to share information packs about the study 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 study information. Young people indicated they wished to take part by asking their social worker to pass on their contact details, posting completed reply slips to the research team or contacting the researchers directly.

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 former carers and/or birth parents still played a positive role in the young person's life, they were also invited to participate in an interview.

Written consent was gained from all participants at the beginning of interviews and all participants were reminded that consent was an ongoing process from which they could feel free to withdraw at any time.

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

RESPONDENT		NUMBER OF INTERVIEWS	
Young people (n=29 <sup>4</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 1: Total number of interview respondents

### 2.3 DATA ANALYSIS

Survey data analysis began by running frequencies and cross-tabulations in SPSS to identify findings relevant to the full range of questions. Relationships between different sub-groups of disabled care leavers were then identified by conducting cross-tabulation of combinations of variables and testing for significance and odds ratios. Transcripts from qualitative interviews were thematically analysed using MAXQDA, a software package that facilitates the systematic analysis of qualitative data (Kus Saillard, 2011). The peer researchers collaborated with the professional research team to develop the coding framework at analysis workshops.

<sup>4</sup> Two young people did not participate in an interview.

### 3.0 PROFILING SURVEY FINDINGS

The survey findings indicated the following key trends and areas for service developments:

1. **Prevalence of mental health.** Over half of the survey sample were 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. More than one in five of the sample had attempted suicide in the previous year. Of these, 43.4% have attempted suicide more than once. However, just over one quarter of these young people were in receipt of Child and Adolescent Mental Health Services (CAMHS) and just under one third were receiving Adult Mental Health Services (AMHS).
2. **Prevalence of intellectual disability and ASD.** Just over one fifth (21%) of the survey sample were in the intellectual disability category and 12.1% in the ASD category. There were more males with ASD and intellectual disability but more females in the mental health category.
3. **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 (18.8%) of the survey sample had more than one impairment type and may have needed access to a range of both disability and/or mental health services.
4. **Reasons for being in care and vulnerability to abuse, neglect or family breakdown.** Young people with intellectual disabilities were more likely than those with mental health needs to have been taken into care because of neglect or emotional abuse. In contrast, those with mental health needs were three times more likely than those with intellectual disabilities to come into care because they were 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.
5. **Placement and school disruption whilst in care.** Almost half of the study sample (46.2%) experienced significant placement changes during their time in care with three or more placement moves. A further 35.9% had one to two placement changes. These high levels of placement change also led to a disruption in schooling. Those with mental health needs are three times more likely than young people with in other impairment categories to have six or more placement changes.
6. **Parenting status.** There were similar rates of parenting amongst the study sample (12.1%) in comparison with the wider leaving care population (11%) (HSCB, 2013). The majority of parenting care leavers were female (63.2%) and 40.7% were under the age of 18. Less than half (47.4%) were living with their children. These findings highlight the importance of including disabled young people in educational programmes on safe personal relationships and parenting.
7. **Living arrangements.** In comparison to trends in the wider care leaver population, care leavers with mental health and/or intellectual disabilities were less likely to stay with former foster carers under the Going the Extra Mile (GEM) scheme. Only 10% of the survey sample were living in former foster care (GEM) placements compared with 27% of the general care leaver population (HSCB, 2013). There was a trend towards those with mental health needs moving on to tenancy arrangements without housing support. In contrast, care leavers with intellectual disabilities were 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. Those with mental health needs were most likely to receive assistance

with accommodation, including floating support. Almost a third of young people with an intellectual disability (31.8%) were not receiving these services.

8. **Education, Employment and Training.** Only one in ten were engaged in employment and only half of these were in paid employment, mostly males in the mental health category. Almost a third (32.8%) were Not in Education, Employment or Training (NEET). This is a higher figure than that for the general care leaver population (21%) (HSCB, 2013). There were no major differences in gender for those in the NEET group, however, over two thirds (68%) were in the mental health category.
9. **Access to 16+ social work and personal adviser (PA) services.** Young people with mental health needs were almost two times more likely to have access to 16+ social work services than those with intellectual disabilities. Almost half of those with ASD (47.4%) and 43.8% of those with an intellectual disability were not accessing 16+ social work services. Whilst the majority of the survey sample (82.8%) accessed support from a PA, a fifth did not have contact with their PA which is concerning if PAs are identified as the main 16+ support for young people. Over a fifth of those with intellectual disability (22.7%) and over a quarter of those with ASD (28.9%) were not accessing PA support, compared to only 11.7% of those in the mental health category. 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. 16+ social work services reduced as care leavers aged out of children's services with half of those accessing these services aged 16-17 years, and 40.3% aged 18-19.
10. **Reduced access to employment assistance.** Whilst almost three quarters of those with mental health needs accessed assistance with employment, over a third of those with ASD and 42.4% of those with an intellectual disability did not, indicating a reliance on other services 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.
11. **Low levels of access to disability or mental health services.** There were low levels of engagement in mental health services. Only one fifth (20.7%) were accessing AMHS, with fewer (15.2%) accessing CAMHS. Almost half (47.1%) of those with an assessed mental illness were not receiving child or adult mental health services. Equal proportions of males and females were accessing CAMHS, however, more females accessed AMHS. Even lower numbers of the survey sample had access to child (5.1%) or adult (13.1%) disability services. The majority of those accessing adult disability services had an intellectual disability (70.7%). Only two young people with ASD (co-existing with intellectual disability) were accessing adult disability services. Despite high levels of co-existing impairment, few young people with intellectual disabilities (n=11) or ASD (n=6) had access to mental health 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.
12. **Access to a befriender or advocate.** Almost three quarters of the survey sample did not have access to a befriender and the majority who did, were in the mental health category. It is concerning that less than one in ten were reported to have access to a mentor and only 5.7% had an independent advocate, indicating a need to for advocacy and mentoring service providers to target provision for disabled care leavers.
13. **Low levels of uptake of direct payments and financial hardship.** Very low levels of direct payment usage (4.5%) suggest a need to raise awareness amongst care leavers and 16+ teams of the opportunity to access direct payments which may provide an opportunity for more creative and personally meaningful ways to support care leavers. In addition, almost one quarter of young people were not in receipt of any benefits and, of these, 17.3% were

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

14. **Youth justice.** A considerable number of young people had received a police caution (40.8%) and almost a third (30.6%) had received a conviction, mostly males and after they came into care. There were higher rates of cautions and convictions for those with mental health needs. The majority of those convicted received a Youth Conference Order, however, almost a fifth received a custodial sentence.
15. **Substance misuse.** Of young people deemed to be at high risk of substance misuse, more than a third were not receiving services to address these risks. An audit of services for care leavers with substance misuse problems would help to inform service development for care leavers engaged in substance misuse.
16. **Withdrawal of leaving care services.** Ages ranged from 16 to 22 years, with a mean age of 18. Over two thirds (69.1%) were aged 16-18 years and over one quarter (28.7%) are aged 19-20 years. The stark decrease in numbers in the older age ranges indicates a focus in 16+ services on younger care leavers with a potential gap in provision for those over 21. 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.

#### 4.0 CASE STUDY FINDINGS AND RECOMMENDATIONS

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. 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; and flexible collaborative practice across 16+, disability and mental health teams.

Practice approaches that were most effective had the following key features:

- **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 and had developed close working relationships with professionals who clearly demonstrated their genuine commitment to the wellbeing of care leavers and understanding of how best to meet their needs.
- **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.
- **Co-locating Services:** Staff working in 16+ teams that 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.

- **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; and 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.
- **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. 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 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.
- **Participation in Post-care Decisions:** Whilst 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.

The findings from the study, however, also indicate clear areas where policies and services need improvement across generic leaving care services and specialist mental health and disability services. 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.

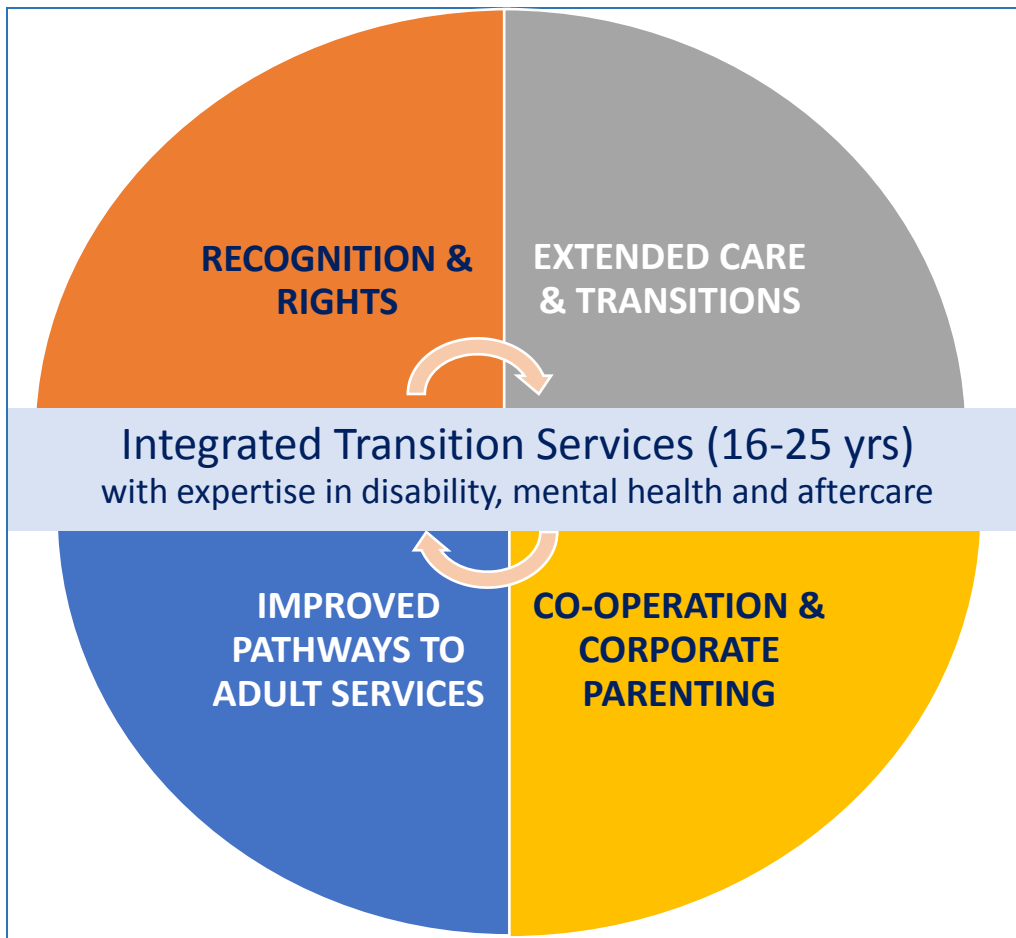


Figure 1: Quadrants for Change.

#### 4.1 Recognition and Rights

A persistent theme in the review of policy and literature was the need for further 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.

The case studies indicated that children coming into care should have an assessment of their mental health and disability related needs to facilitate earlier diagnosis and to inform decisions about the most appropriate care to meet their needs. In preparation for leaving care, young people also need earlier re-assessment of mental health and disability related needs to facilitate timely transition planning and access to adult services.

Case study participants indicated that there were areas of improvement required for care leavers in general that would particularly benefit care leavers with mental health and/or intellectual disabilities. For example, diversifying pathway planning approaches through use of technology and less formal planning processes would benefit all care leavers but would be particularly useful for those with mental health and/or intellectual disabilities who need alternative and more person-

centred approaches to engagement. In addition, care leavers with mental health and/or intellectual disabilities should have greater access to befrienders, independent advocates and educational programmes about sexual and personal relationships and effective parenting. A recurring theme in the case study findings was the importance of consistent professional relationships and access to a worker who genuinely cares. Young people greatly valued close working relationships with practitioners who were strengths-based and person-centred in approach.

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 the complex social security benefit system. Several young people accrued arrears on payments due to confusion about benefits and some had taken out loans to cover repayments which were difficult to manage on a very low income. There was also very limited awareness and uptake of direct payments or self-directed support packages.

Finally, the case studies found that care leavers with mental health and/or intellectual disabilities experienced stigma on the multiple grounds of their care leaver status, disability and mental health. Study participants also experienced bullying, intimidation and abuse which was rarely adequately addressed by public services. Such discriminatory treatment must be proactively addressed.

#### **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. Assessments of health and disability should be undertaken on entry to care and as young people prepare to leave care. Pathway planning approaches should be more creative and person-centred to engage those with mental health and/or intellectual disabilities.
3. There is also a 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 full access to leaving care services they are entitled to. Befriending and independent advocacy services should also target these care leavers.
5. A review of welfare benefit usage amongst 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.
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.
7. Professionals must also be supported to develop their practice methods and skills in providing person centred, relationship based practice 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.

#### **4.2 Improved Pathways to Adult Services**

Across Trusts there was a lack of clarity about pathways from child to adult service provision. Eligibility criteria for access to specialist mental health or disability services based on a strict

adherence to severity of impairment failed to address the ongoing needs of care leavers with mental health and/or intellectual disabilities. There was much concern among social workers and carers about barriers to accessing mental health or disability services for those without a clear diagnosis. Those who had co-existing intellectual disabilities often had to rely on learning disability psychiatric services to meet their therapeutic needs. In addition, there were delays in assessments of mental health or disability for young people ageing out of care. For young people with very complex needs, there were also delays in decisions about the provision of adult services due to lack of agreement on funding arrangements.

Young people also struggled to adapt to the AMHS service culture which, in comparison to CAMHS, had a more rigid, clinical and time limited focus on medication or diagnosis. Young people also reported being discharged from AMHS for failing to attend up to three clinical appointments despite genuine reasons for non-attendance. As a result, care leavers with ongoing mental health needs were often disengaged from AMHS. It is important, therefore, 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. In addition, there should be easier routes to AMHS for care leavers who have difficulty registering with a GP, including a change to current practice that does not allow 16+ social workers to refer directly to AMHS.

The case studies found a lack of suitable, long-term accommodation for care leavers with mental health and/or intellectual disabilities and in-patient psychiatric care for young people. In addition, there were 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. There were also geographical variations in the availability of services for care leavers with lower levels of provision in more rural areas.

The case study findings also highlighted 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 could have a greater understanding of disability and mental health issues and disability or mental health organisations could build on 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 ongoing 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.



### 4.3 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. Those 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.

Most young people were positive about 16+ services with some having valued relationships with a 16+ social worker or PA who showed genuine commitment and care for them. 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. There was concern for those with ongoing needs who disengaged at an early stage from 16+ services and indications that Personalised PAs (who could be former carers) may be well placed to provide more individualised support for these young people.

Young people with mental health and/or intellectual disabilities often needed more time to find a safe place to live, work out family relationships and learn independent living skills before they got involved in an education/training course or found work. Whilst these care leavers needed ongoing aftercare support, 16+ services reduced as young people aged out of children's services at 18 and withdrew at 21 for those not in education, employment or training (NEET). Raising the age at which young people cease to be supported by 16+ services was strongly recommended as care leavers with mental health and/or intellectual disabilities are vulnerable to poor outcomes in all areas of life well into their twenties and should be supported for longer than is currently available.

Some young people were very positive about CAMHS, highlighting the benefits of their flexible and therapeutic interventions. However, CAMHS also ceased when care leavers reached 18 and needed to be extended for care leavers who require ongoing therapeutic intervention from trusted mental health professionals who understand their care histories. Indeed, 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. Some young people with diagnosed mental illnesses were not receiving specialist support despite ongoing mental health needs, including ongoing self-harm and suicidality. Social workers in 16+ teams were concerned about managing high level risks for these young people without access to specialist adult services.

#### **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 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.
15. CAMHS could be extended to 21 or 25 for care leavers who require ongoing therapeutic intervention from trusted mental health professionals rather than an abrupt transition to adult mental health services which has a more clinical approach focused on diagnosis and treatment.
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.

#### 4.4 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 as young people for whom the HSCT has ongoing corporate parenting responsibilities, rather than such duties being viewed as the sole responsibility of Looked After Children (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.

The study findings also highlighted the need to share knowledge and expertise across specialisms and facilitate more creative forms of collaborative working. 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 and adult services to avoid crisis driven transitions and abrupt moves to adult care placements.

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. 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, and provide services to meet these identified needs, 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.

#### 4.5 Integrated Transition Services

Many of the challenges for care leavers with mental health and/or intellectual disabilities were related to barriers to accessing the services they require to meet their multiple and diverse needs. 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 that 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. 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.

The development of this 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 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. If this new model of integrated transition service provision proves to be successful, consideration should be given to its roll out to other Trust areas and for wider groups of care leavers or young people with mental health needs/disabilities in transition to adult life.

**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.

#### **4.6 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 findings also provide direction on areas for future research in the following five main areas:

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 care leavers' experiences of the criminal justice system was not a core aim of the study, however, the study findings 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.

## **5.0 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. Given the lack of attention to the experiences of these care leavers in both research and policy, the study findings make 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 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. 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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