You Only Leave Once?

The Views and Experiences of Care Leavers with Mental Health and/or Intellectual Disabilities: Case Study 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 NI (DHSSPSNI, 2015). 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 case study phase of our research that sought to address this gap in knowledge by investigating the experiences and views of care leavers with mental health and/or intellectual disabilities[1] in NI. Care leavers with mental health and/or intellectual disabilities are the main focus because the study is funded under the Bamford[2] programme of research and these are the two main impairment categories within the care leaver population, often co-existing.

1.1 BACKGROUND TO THE STUDY

There were three key stages of the overall 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 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 (the focus of this report). A summary of the key messages from earlier phases of the study and the service context is presented below. Readers can also access an overall final report summarising all stages of the study (Kelly et al., 2016b) on the following web link: http://www.research.hscni.net/bamford-implementation-commissioned-call-portfolio.

1.1.1 Policy and Literature Review

The policy review highlighted a broad commitment to promoting the rights of disabled children and young people in NI. The following six core themes were 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 support, combined, when necessary, with specialist provision; and
- Participation of service users in decisions affecting their lives.

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[1] 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.

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

Whilst the range of strategies and service frameworks across departmental areas highlight these common themes, they often neglect to specify just how these should be implemented in the short and long-term and what guidelines or duties are in place to ensure they are effective. The review also raised questions about the impact of various forms and levels of policy on service delivery and development given the range of strategies, action plans, service frameworks and policy initiatives relevant to child, disability and mental health services.

The review also highlighted the invisibility of care leavers in disability and mental health policies and, similarly, the lack of attention to disability and mental health issues within child care or leaving care policies. It could be assumed that policies addressing the universal needs of all care leavers or disabled young people automatically include care leavers with mental health and/or intellectual disabilities without their specific mention. However, it is more likely that the lack of consideration to this particular group across policy domains reflects their position as an overlooked group. This population requires explicit attention 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.

The review of literature identified a very limited evidence base in relation to disabled care leavers and studies that have been undertaken are predominantly qualitative and small-scale (Ellem et al., 2012; Fudge Shormans & Rooke, 2008; Mendes et al., 2013; NFCA, 2000; NSW Ombudsman, 2004; Rabiee et al., 2001). There is a larger body of research on the mental health needs of care leavers which is generally large scale, quantitative and predominantly American (Courtney et al., 2007, 2012; McMillen et al., 2005; Pecora et al., 2003, 2005; Yates & Grey, 2012). These studies have been mainly concerned with measuring the extent of mental illness or disorder using diagnostic scales or standardised measures. Further qualitative and participatory research informed by a recovery model of mental health, therefore, would help to develop the body of research on care leavers with mental health needs. As there is an absence of research with care leavers who have borderline/ undiagnosed impairments, are homeless, are not engaged with services or come from ethnic minority and cultural backgrounds, future research should actively seek to include these neglected groups of care leavers.

The empirical research that is available clearly indicates that care leavers with mental health or other disabilities face additional challenges in relation to education, health, employment, housing and social support (Cashmore & Paxman, 2007; Courtney & Dworsky, 2006; Dixon et al., 2006; Fudge Schormans & Rooke, 2008; Mendes et al., 2013; NSW Ombudsman Review, 2004; Pecora et al., 2003, 2005; Vinnerljung et al., 2006; White, 2011).

Higher risks of substance misuse, suicide ideation, depression, criminal behaviour and homelessness are repeatedly cited, alongside difficulties with accessing specialist services due to narrow eligibility criteria and limited co-ordination across child and adult programmes of care (Dworsky et al., 2006; Edwards, 2010; Ellem et al., 2012; Fudge Shormans & Rooke, 2008; Goldblatt et al., 2010; MacDonald, 2010; Mendes et al., 2013). Previous research also identifies features of effective policy and practice meeting the needs of care leavers with mental health and/or intellectual disabilities, including:

- Strengths-based, person-centred planning targeting young people’s self-determined priorities;
- Involvement of care leavers in decisions about their post-care lives;
- 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.

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 (Daining & DePanfilis, 2007; Dixon et al., 2006; Fowler et al., 2011).

1.1.2 Service Context

Health and social care services in NI are delivered though 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 16th birthday. The status of care leavers can be further sub-divided 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 leaving care until they transition to adult disability services. 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).

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.

Disabled care leavers, therefore, 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.

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.

1.1.3 Key Findings from the Profiling Survey

The second stage of the study involved a profiling survey completed by social workers which, for the first time, captured the characteristics of the population of care leavers with mental health and/or intellectual disabilities in NI (n=314). Based on the findings reported, the following key trends were identified, including 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 had more than one impairment type and were, therefore, likely to require 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.** Variances in reasons for being admitted to care were notable across the two dominant impairment categories. Young people with intellectual disabilities were 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 were three times more likely than young people with intellectual disabilities to have 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 should inform 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 were parents reflect those for the wider leaving care population. The majority were female, 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 were less likely to have the opportunity to stay with former foster carers under the Going the Extra Mile (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. 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 and may present further risks for these young people.

6. **Access to 16+ social work and personal advisor (PA) services.** 16+ services were 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 Autistic Spectrum Disorder (ASD) have equal access to the full range of leaving care services they are entitled to. Most of those who had a PA had regular contact with them, however, a fifth had 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 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 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 were reported for those with intellectual disabilities or ASD. Similarly, numbers remained 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 were reported, 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 did not have access to a befriender and the majority of those who did were 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 used 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.

In conclusion, the survey findings indicate clear areas that require targeted policy and practice developments. However, we need further research to develop our understanding of the needs and experiences of this population of care leavers. The final qualitative phase of this study provided an opportunity to further explore these issues through case file review and interviews with care leavers, parents, carers and social workers. The following section of this report presents the methodology, findings and recommendations of this case study phase of the research.

2.0 METHODOLOGY

The final stage of the study used a case study design with the overall aim to investigate the experiences and perspectives of care leavers with mental health and/or intellectual disabilities. The objectives for the case study phase 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 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 how and why 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 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. 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, the professional researcher interviewed current or former carers, social workers or PAs, and, where appropriate, birth parents. Approval from each Trust's research governance team and ORECNI was secured prior to the commencement of data collection.

2.1 SAMPLING OF CASE STUDY PARTICIPANTS

A total of 31 young people took part in the case studies. As outlined in Table 1, 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

2.2 RECRUITMENT AND GAINING CONSENT

The social worker (from 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 as 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 researchers 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 participate 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 was also alert to the young person's verbal and non-verbal cues during their visits and, when appropriate, checked with the young person if they were happy to continue or wished the interview to end.

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. On advice from the care leaver advisory group, where family dynamics were tense or disruptive, birth parents were not approached.

Written consent was gained from all participants at the beginning of interviews. Participants were reminded that consent was an ongoing process and they were 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 CASE FILE READING

Young people’s social care case 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 the 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.

2.4 PEER RESEARCH APPROACH

Following on from previous studies that successfully involved care leavers as peer researchers (Broad and Saunders, 1998; Dixon et al., 2015; Edwards, 2011), 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 following sub-sections below outline how peer researchers were recruited, trained and supported during their involvement in the study. As the peer research aspect of the case study methodology was an innovative approach, an independent evaluation of the peer research process was undertaken and the main findings of this evaluation are also reported below.

2.4.1 Recruitment of Peer Researchers

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.

The advertising campaign yielded 21 applications from care experienced young people aged between 18 and 25 years. These were mostly submitted with the support of social workers and project workers, although some of the young people made their applications independently. Letters of invitation for interview were then sent to applicants detailing time and venue for interviews. In order to assist them in their interview preparation, interviewees were provided with two questions to consider in advance of the interview relating to their relevant skills and experience and the potential challenges of peer research. Three young people declined an interview and a fourth person was not contactable to arrange an interview despite several attempts to make contact via his social worker and homeless shelters where he had been living. Five young people did not attend for interview and did not contact the researcher to provide a reason or seek an alternative date for interview.

Twelve young people were interviewed over four interview sessions in Derry and Belfast by an interview panel comprising the PI, lead researcher and VOYPIC representative on the study. A series of set interview questions were asked by panel members focusing on the candidate's relevant skills and experience and the issues affecting young people with mental health needs and/or intellectual disabilities leaving care. The practicalities of availability to take part in training and interviewing and criminal record checks were also discussed at the interview.

Interviewees were scored on their interview performance over the following six categories with a possible total score of 60 points: motivation, understanding of care leaver experiences, relevant skills, relevant experience or qualifications, interpersonal communication and insight into personal valued and challenges. All applicants who scored 30 and above were offered the position. Only two interviewees were unsuccessful at interview. One of these young people arrived very late for interview and his performance was below the standard required to be offered the position. He was offered another interview date which was subsequently declined. The other unsuccessful applicant did not express motivation for the role, indicating that she only applied because her social worker thought it would be a good idea and performed poorly across all areas of the interview. This candidate was given feedback on areas for improvement before being offered a second opportunity for interview but also declined.

The 10 applicants who were successful in the recruitment process were aged between 20 and 24 years with a range of care experience including previous kinship care, foster care and residential placement settings. Candidates also demonstrated a range of relevant experience, such as working with young people as peer mentors, college class representatives and volunteers in the voluntary and community sector. 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, issues relating to confidentiality and mental health challenges. Indeed, some disclosed details of their own mental health and self-harming issues. 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, attended by the research team, peer researchers, other academics engaged in peer research and representatives from voluntary organisations working with peer researchers. These workshops gave the peer researchers an opportunity to meet for the first time and to find out more about the study and the role of the peer researcher.

Following the orientation workshops, four of the ten 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. Of the six young people who proceeded to training, one applicant did not attend two days of training and, as a result, effectively withdrew from the process. In total, five young people proceeded to complete the initial training programme. However, during first round of interviews, one of the five peer researchers exited the project due to personal circumstances. A new peer researcher was recruited via VOYPIC midway through the project to replace this person who left. He had prior training on ethical issues and experience of advocacy and was given an additional short training course with the PI. Peer researchers and the wider research team indicated at the end of the study that, in contrast to the 10 peer researchers that had been planned for the study, the smaller size of the peer research team was helpful and led to close working relationships.

2.4.2 Training and Support of Peer Researchers

All six successful interview candidates were required to attend and 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. As young people had limited prior experience of disability issues and peer research, particular emphasis was placed on clarification of the role and developing knowledge and skills for research with care leavers with intellectual disabilities. 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. This preparation helped to ensure participants understood the peer research role and also that unnecessary information about the peer researchers' own care experiences were not shared with research participants.

As noted above, by the end of the five day training programme, one peer researcher had withdrawn due to lack of attendance. The remaining five candidates attended an assessment day when they role-played two interview scenarios and engaged in reflective exercises on the strengths they brought to the study and the areas they felt they needed to improve on (for example, time keeping or use of silence). All participants then received a certificate of completion of the training and a pack containing all of the training materials and preparatory information for interviews, including the scripted introductions and interview schedules.

Following in-depth discussions about levels of support peer researchers felt they would require to carry out initial interviews, it was decided each peer researcher would be supported by an experienced 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 an external source of support. However, they preferred more informal direct support from the researcher before and after their interviews. Most peer researchers needed assistance with travel to interviews which offered an opportunity for briefing and debriefing on car journeys. For one peer researcher who travelled independently, time was set aside to meet before and after interviews to ensure an opportunity for briefing/debriefing and reflection with the professional researcher. 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.

2.4.3 Evaluating the Peer Research Approach

The peer research methodology adopted for the study was independently evaluated and further details of the findings are available in the evaluation report (Dowling, 2016). 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 linked to the rapport developed with participants; an informal style of interviewing which enabled open and in-depth participant responses; a 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 study 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 future careers and engagement 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 and coordinating interviews to ensure they were scheduled at a time that suited the participant, peer researcher and accompanying researcher. One way to avoid this in future studies would be to offer a fixed term part-time position for peer researchers so they have dedicated time to work on the study. 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 to particular participants with whom they had built a close rapport. 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.

2.5 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[3])		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	
TOTAL NUMBER OF INTERVIEWEES	**84**	**TOTAL NUMBER OF INTERVIEWS**	**131**

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. 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, some 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 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

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[3] Two young people did not participate in an interview.

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. In addition, the two young people who joined the study from a previous project were interviewed by the professional researcher they were familiar with, rather than introducing a peer researcher to second and third interviews. 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. One of these young people was experiencing a deterioration in their mental health and the other relocated to another part of the country and ceased all contact.

The third round of interviews occurred approximately six months later with 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 by the professional researcher at earlier stages of the study and three were interviews previously undertaken by peer researcher who later exited the study, therefore, 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. For example, in cases where young children or other family members were expected to be present, interviews were co-produced to help keep the interview on track, and manage family dynamics to allow the young person to give their own opinion. 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.

2.6 DATA ANALYSIS

All transcribed data was uploaded into MAXQDA, a qualitative data analysis software package that facilitates the systematic coding of qualitative interview data as themes emerge during the analysis process (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. This process helped to identify additional codes and confirm those that already existed. For the second round of interviews, peer researchers independently coded the interview data using the coding framework established in MAXQDA. At this stage of analysis, some new codes were added to reflect the changes in young people's lives over time. For the final round of interviews with young people, a sample of interviews were coded jointly by peer researchers and professional researchers at an analysis workshop day. 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 were 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 for 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.

2.7 STUDY LIMITATIONS

It is important to note that the case study sample was selected from the survey sampling frame which only captured data on care leavers known to Trusts at 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 if they exited services early.

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 all young people with mental health and/or intellectual disabilities leaving care. However, the research team 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 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 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. Young people described 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. In addition, care leavers described their experiences of mental health and disability and the impact of impairment on their leaving care experience and daily lives.

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 presents 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. During interviews, professionals discussed issues relating to young people involved in the study but also drew on other casework and their wider experience of working with care leavers with mental health and/or intellectual disabilities.

3.1 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.

3.1.1 Mental Health Needs

Young people in the mental health category had been diagnosed with a range of mental illnesses including depression, anxiety disorders, Post-Traumatic Stress Disorder (PTSD) and eating disorders. At the time of the study, some care leavers were attending appointments with mental health professionals or taking 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.

Poor mental health was an ongoing issue for many of the young people with some experiencing fluctuating mental health, as the following social workers explained:

> *She will go through periods where her mental health is stabilised and then go through periods where it's not... Certain factors trigger it and relationships are a big thing... feeling that she has been rejected by her mother… a breakdown in a relationship* (Joanne's social worker).

> *I think her current mental health seems quite good but I have seen it deteriorate very rapidly... In terms of risks she is possibly non-compliant with her medication… and if there is a period of non-usage of that it will lead to rapid deterioration...* (Connie's social worker).

Mental ill health impacted on a range of aspects of their lives, such as, friendships, education or employment. For example, Joel was unable to fulfil his ambition of moving to a new area to attend college due to his social anxiety and depression:

> *I just took a real anxiety and said 'I am not going'. If I had gone there I know myself I would have come home in a body bag... 'Cos of me ups and downs.*

Others had found strategies for managing times when they were in low mood with support from carers including exercise, avoidance of substances that could exacerbate moods, talking to others and keeping busy:

> *I know how to spot it now... I don't drink because I would have just got drunk on my own. I don't keep drink in the house at all now. It would be too easy. I just go for a run* (Chloe).

> *I've got my mental health finally under control. If I am feeling a bit low or a bit depressed, I go and talk to somebody now. Even if it's just a simple conversation. I get myself up and out every day… if nothing works just ring my aunt and she'll come… If I'm having a really bad day I would usually take myself off and just go for a walk… that's what works best for me* (Lorna).

> *It varies every day. I'm just trying to… keep busy… I'm going to have to solider on* (Jamie).

> *It would affect me from time to time. But I think it's just learning different ways to cope with it… speaking to somebody… not being alone with it* (Louise).

Former carers also commented on the range of effective coping strategies young people used to address episodes of low mood, including self-care activities and time out:

> *She basically just stays in her room. She just keeps herself to herself because if you push her she'll... blow up... get violent. So she's learned that the best thing to do is to stay away from everybody... or walk the dog for two or three hours just to get herself out of the house and clear her head which is brilliant… cos it used to be that just all hell broke loose* (Lorna's kinship carer).

> *She would have wee dips in her moods... If she's nothing to do, she probably starts over thinking... She can get very, very low self-esteem to the extent that she believes she's truly ugly... You could send her to get her nails done or her hair... that seems to bring her round... It would be a wee blip but then she gets up dusts herself down and she gets on with it* (Joanne's former carer).

For some young people, a clear diagnosis was important in terms of understanding the effects of their mental illness. For example, Louise welcomed her diagnosis and appreciated having knowledge of the symptoms and information to help her to understand and manage her condition:

> *It was good that they put a finger on it and knew, you know, this is normal. That kind of helped me when I was freaking out... it was like 'Oh you're not totally odd, you're not totally strange'. There was some reassurance of it in a sense… It did help 'cos 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.*

Similarly, Joanne received an additional diagnosis during the course of the study which helped her to further understand her mood and feelings:

> *Well the bipolar was diagnosed a couple of years back and then the borderline personality disorder was diagnosed... I never really understood how I felt... and times I could have been in a real mood and not knowing why. Whereas now, at least I have a reason and I know what's going on with me. So it's kind of a good thing. But at the same time you're like 'Why am I so different? Why this disorder?' Cos it's not something everybody has.*

In the cases above, young people found that a diagnosis helped them to understand their mental ill health and identify coping strategies. However, not all care leavers were happy to have a diagnosis and some disputed their diagnosis, often due to a lack of information about their mental illness and/or an awareness of stigma associated with mental illness. For example, Sara remained, to a certain degree, in denial about her condition:

> *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.*

Similarly, Tina's social worker explained how she was reluctant to have a further mental health diagnosis:

> *There was some discussion of her being diagnosed with bipolar disorder and she was totally going to disengage with any support services cos she was so afraid of having that label... She thinks it will impact on her chances of being employed* (Tina's social worker).

For some care leavers, there was a clear improvement in their mental health during the course of the study. For example, Tony associated an improvement in his mental wellbeing with increased socialising with other people after a considerable period of isolation:

> *I would say my mental health is a lot better than what it was... Just being able to get out and meet new people and being forced to not seclude myself… So being dragged out to the bar to have a drink or to a social gathering.*

In the above cases, young people were mostly feeling positive about their mental health by the end of the study and had effective techniques for addressing isolation and low mood. However, other young people were not managing so well. For example, by the end of the study, Norah was struggling to cope with depression and the negative side effects of medication:

> *I've had quite a lot of low mood… It's a certain part of the day where you just kind of slump and then it kind of stays that way... It affects your daily life… you just can't be bothered talking to people. Kind of isolating yourself. Just kind of feeling stuck as well. It just kind of consumes you. It just creeps up on you.*

Jake also felt his mental health was declining. By the final interview, Jake's social worker had referred him for counselling. However, he felt unable to engage with counselling, preferring instead to either cope alone or rely on staff from his former children's home who knew him well:

> *A referral [for counselling] has been made but I'm not willing to engage… I'd rather go through it alone... Just the last six months, I got quite low… Maybe like a few staff from one of the children's homes I still keep in touch with... I only see them here and there… I talk to them ones better than anyone else cos they kind of know me and my past… rather than someone… that actually don't know me… They're more close friends and they view me the same way* (Jake).

David’s mental health had also taken a downward turn during the study. By the final interview, he had attended his GP and was taking antidepressants again after a period of not requiring this medication. David linked the deterioration in his mental health to his relationship with his mother:

> *When I speak to my mother… I completely change. I get really uptight and annoyed… I actually had to be put back on anti-depressants.*

Some care leavers also indicated that their mental ill health was associated with an 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. For example, Lorna connected her poor mental health to both being taken into care and also her in-care experiences:

> *A lot of my mental health problems came from being taken away from mum and dad... and being in care… I had ten foster families and two children’s homes… sort of thrown from pillar to post... once I sort of hit my teenage years and was able to understand everything a bit better, that’s whenever problems started.*

Social workers commented on the ongoing impact of previous abuse or neglect and the separation from birth family on the emotional wellbeing of care leavers:

> *He has had a very difficult and traumatic past and he needs a lot of support around managing and regulating his emotions and feelings... He just gets so overwhelmed... He struggles because he has those attachments to his mum* (Simon's social worker).

> *There had been longer term issues from her past that she does struggle with both in relation to siblings and her parents. Just her own self-esteem and self-confidence then factors like education, relationship with peers... a combination of all of that led her to a very low point in her life* (Laura's social worker).

Carers who kept in regular contact with young people were in advantageous positions to recognise a deterioration in young people's mental health, often in early stages of decline. Chloe’s former carer, who spoke to her on a daily basis, was sensitive to changes in her behaviour and mood. This carer identified symptoms signalling a mental health downturn and took supportive action in response:

> *Sometimes if Chloe’s very down, you might have to go looking for her and find out what’s going on… She starts to get quieter... one word answers or she doesn’t answer texts… Or she hasn’t washed her hair... When you see those things starting to go… when there’s a dip, I go to her... Try to brighten her up a wee bit… It just goes up and down like that* (Chloe’s foster carer).

Indeed, social workers noted how carers offered intensive support to care leavers when they experienced a deterioration in their mental health:

> *There was a period of time when she did move back into her former foster home for four or five weeks because of her emotional health and having difficulties living independently... Her carer would be very clued into her emotional needs, her mental health, issues... even having a meal a couple of times a week with her… She likes to come over to her former carer’s* (Chloe’s social worker).

Whilst strained birth family relationships could be a trigger for a deterioration in mental health, birth family members could also play an important role in supporting the emotional wellbeing of care leavers, especially kinship carers. For example, Lorna tended to stop eating and administering her insulin during periods of stress or when her mental health was at a low ebb. Lorna’s kinship carer described how threats to withdraw her support encouraged Lorna to cease this behaviour which had on more than one occasion resulted in her becoming seriously ill and hospitalised:

> *She'll stop eating, she'll stop taking her insulin... she ended up in intensive care… And I says to her... 'if you ever do this again you're not coming back to my house'… It was the hardest thing I ever did… but she has not once messed around with her diabetes which for Lorna is amazing… Finally the penny dropped* (Lorna's kinship carer).

In such cases, a severe mental health crisis or period of hospitalisation was a turning point in the lives of care leavers who then began a journey of recovery:

> *In terms of her own mental health, her hospitalisation into intensive care was a real turning point for her... I think that frightened her because she had put herself in the situation... certainly then it's been upwards... Her mental health has been greatly improved* (Lorna's social worker).

Social workers emphasised that positive informal support networks could help to prevent a deterioration in mental health for care leavers, including support from birth family members:

> *Those that haven't got a mental health need on my case load... usually have family support and those with mental health needs don't have that family support and I think that's a stark contrast* (Laura's social worker).

However, as Laura's social worker explained, many care leavers had very limited support networks and experience of being in care had contributed to their disconnection to the local community and ability to make and sustain friendships and interests:

> *The isolation of all care leavers is horrendous. Having come through the care system that closeted them, they don't become part of the community... It's very difficult to make those linkages for them because in association with their mental health comes that low self-esteem, that inability to make and sustain friendships because they don't know how to... So it's the importance of giving our care leavers normal activities... It needs to be somebody from outside of social services because when they leave care that's the support they are going to go to. Laura has been in care since four. She has no other world so, thus, she just drops like a hot brick when she comes to leaving care* (Laura's social worker).

3.1.2 Suicide, Self-harm and Substance Misuse

In total, 11 case study participants had attempted suicide. For most of these young people, suicide attempts were linked to a personal crisis (e.g. a breakdown in a personal relationship), bullying, difficult family dynamics and/or substance misuse:

> *I didn't take the break up too well... I was drinking every night... and just being by myself. And then there was one night... I started taking all these tablets... and overdosed* (Jamie).

> *I had that depressive state… It was nothing to do with home. It was just to do with being bullied. I thought it was just the easier way out* (Danny).

Laura indicated that her attempts to end her life were linked to placement moves and separation from her birth family:

> *I think it was because of moving about so much and I couldn't keep in contact with my friends and my family... that was really hard. And just moving and moving and moving... I just got really stressed.*

Reflecting the important role of former foster carers, Chloe described how her attempt to end her life was intercepted by an impromptu visit by her former carer who contacted emergency services:

> *I took an overdose and ended up in hospital... My front door… wasn't locked and my foster mother… phoned an ambulance. They said if she hadn't come into the house I would probably be dead.*

Diane, in her final interview, also disclosed having spent a recent period in hospital following a drug overdose. She had been struggling in recent years with drug addiction and described events shortly before a prison term:

> *I was in hospital… before I went to prison. This whole year, I can barely remember anything... It was just full of drugs and... I couldn't hack it no more... I was coming off them and I didn't want to be on them. So I got to the stage where I was just trying to kill myself, every day for a solid week… through tablets… I wanted to die.*

Some social workers worked with care leavers who had attempted suicide and for whom they had serious concerns about the risks they posed to themselves, as Joanne's social worker explained:

> *She's not been taking her medication for low mood, she has been self-harming and cutting and she also attempted overdoses... So she is not in a good place... She has stated that she has a possible plan maybe to carry out a suicide attempt and that she will do that when her child is not around... I would be very concerned about her... It's about putting a safe care plan in place for her for that moment. It's for that day because they can't see past today... and there is protective factors there I believe will stand her in good stead... while she is still engaging with me and other professionals* (Joanne's social worker).

Similarly, Louise's social worker described a time of concern for her wellbeing:

> *She was very very unwell. She was adamant that she wanted to end her own life... She didn't see any benefit in staying alive... she was actively suicidal for almost the first year that we met... She was very flat, very emotionless, very difficult to engage... despite all of that you could see that she was a fantastic young person, very intelligent, very bright and you could reach her with a sense of humour there.*

Social workers spoke of the stress of managing high level risks of suicide for young people:

> *That's the bit I don't like about my job, you are running with huge risks with youngsters with mental health problems... Suicide is a big risk... You hope what you have done with that young person has been adequate for when they do disengage and when they are high risk takers it does impact on you* (Laura's social worker).
>
> *Suicide is a big risk for us to manage… We run with very high risks in the 16+ world for a lot of our young people* (Lorna's social worker).

Social workers also struggled to cope with the aftermath of suicide among young people who had been on their caseloads:

> *We were involved with a young man who unfortunately did die after he was 21 and... my involvement with him was for a very short period of time and was it good enough?... You have to live with that* (Laura's social worker).

> *We've had a number of suicides in our team with our over 18 population... It is very difficult for staff to deal with suicide especially where there had been no indicators that suicide was even on the horizon with them* (Lorna's social worker).

Self-harm and Self-care

Most young people in the sample had self-harmed with varying degrees of severity and some were still engaging in self-injury by the final interview stage. Imogen described her self-harm by cutting, reasons she resorted to it and how she eventually managed to reduce this coping behaviour:

> *I self-harmed from I was about fourteen... I only really stopped self-harming about three, four months ago... I suppose 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 used to cut near enough every day, probably twice a day… Most of the time I would love to self-harm 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.*

By the end of the study, Joel was still self-harming and, although he felt these behaviours had reduced in terms of severity and regularity, he was not accessing any informal or formal support in relation to this self-harming behaviours.

Other study participants self-harmed through substance misuse. For example, Susan, who spent the duration of the study moving between secure and intensive support units, was regularly self-harming with drugs and alcohol and engaging in other risk taking behaviour. Susan's social worker felt that she underplayed the negative effects of substance misuse on her health and wellbeing:

> *She is literally just totally out of it because of the substances... We've had to call paramedics... Our young people are at major risk of those legal highs and then if they have a mental health issue as well then they are at even greater risk of having a psychotic episode by taking these substances… Another risk would be that she would move on to other drugs like injecting heroin... One of her friends is using heroin so it's only a matter of time... She will be very dismissive of it... It's all very like 'ah no its fine that will not happen to me'* (Susan's social worker).

However, during the last interview, Susan expressed a realisation of the dangers posed to her health and safety if she continued with the same level of substance misuse:

> *If I keep taking herbal [legal highs] my mental health will be away with it… I'm not gonna take it. It's ruining my mental health… It will be ten times worse… If I keep going the way I'm going, I'm gonna end up dead* (Susan).

At this stage of the study, Susan felt positive about her move out of secure care into supported living as a new beginning in her life and a time when she hoped to abstain from drugs and alcohol.

Substance misuse was a key feature of the lives of many of the young people and, for some, use of alcohol or other drugs was a way of self-medicating. Some of the participants revealed regular cannabis use and, as Diane explained, this drug helped to stabilise her emotional state and agitation:

> *I am not addicted to it. I could quit at any time... But see to be honest, it actually helps me. It helps me stay on a level everybody else is at… stay on a normal level of conversation.*

Social workers, however, had serious concerns about ongoing substance misuse for some young people and expressed dissatisfaction with the lack of addiction services:

> *We were so concerned about her level of drug misuse... CAMHS contacted Drug and Alcohol services within the Trust for in-patient services... but there was no real service there* (Norah's social worker).

Birth families could play a part in care leavers’ misuse of substances by either providing or encouraging risky behaviours. In addition, stressful relationships with family members could trigger mental health decline and engagement in substance misuse. Drug taking behaviour was also noted as being more prevalent for those leaving residential care:

> *In a residential unit you will definitely be exposed to it. If you are not taking them yourself you will see other people taking them... You'll probably be offered them you might even be pressurised into taking them* (Susan's social worker).

For some young people, social workers were worried that substance misuse linked to engagement with a negative peer network led to additional risks of sexual exploitation and criminal activity, as Diane's social worker explained:

> *The current issues are going to be the drug misuse... She has a tendency to make poor choices in relationships... violent relationships... and, again, offending... When she slips back into the drugs and into the alcohol, she goes out with people who are not going to have a positive influence on her and then she sort of gets drawn back into that... and she has a suspended sentence* (Diane’s social worker).

Despite some young people having a greater awareness of strategies to improve their emotional wellbeing, some care leavers tended to neglect of their general health. Tony, for example avoided seeking medical advice or assistance from his GP and did not attend a dentist regularly:

> *I don't really attend the doctor or the dentist. I know I should … I don't see the need of it. I don't go to the doctor's unless I have broken my leg or something ridiculously serious.*

Chloe’s former foster mother was concerned that Chloe did not prioritise her tight budget towards essentials for daily living:

> *She is struggling with her finances and her cigarettes and her car are her priority so she’s not maybe buying herself food or heating her home* (Chloe’s foster carer).

Although some young people spoke of activities such as, attending their local gym or playing football, most young people did not take regular exercise or live generally healthy lifestyles, citing lack of motivation as the main reason:

> *I don’t mind like doing exercises and stuff like but I do see myself sometimes just sitting in the house all day… I don’t really do much at the weekend I just play the PS4* (Jamie).

Social workers shared experiences of working with care leavers who struggled to care for themselves and were often self-neglectful and had low self-esteem:

> *The issues now would be personal hygiene, self-care... Simple things like getting his teeth seen to... He won't get it done... He's in this kind of unhealthy cycle whereby there's junk food eating on a daily basis. There's no daily routine. There's no regular meal pattern* (Danny's social worker).

> *I am working with a young man with complex needs... He still doesn't wash... He doesn't eat from the second day he gets his benefits til the next week he gets his benefits... I actively dip in and he allows that... a patch up service... We will ring up and say 'Do you want to go for a McDonalds this morning?' knowing he hasn't eaten for five days* (Laura's social worker).

3.1.3 Experience of Impairment and Disability

As noted above, seven case study participants were in a sole disability category (five with an intellectual disability and two with ASD) and 12 participants had co-existing impairments across the domains of intellectual disability, mental health and/or ASD. These young people were described as having a range of borderline to severe levels of impairment. In addition, several young people also had physical or sensory impairments.

Reflecting the points made above in relation to mental health diagnoses, some young people with mental health and/or intellectual disabilities recalled a sense of relief associated with being given an official diagnosis as it helped them to understand the impairment effects they experienced on a daily basis. Most participants offered explanations of their impairments based on definitions given to them by professionals, parents or carers. For example, Dawn explained:

> *I am told that I have a disability which is the learning because I am special needs.*

Several young people had waited some time for a diagnosis. For example, Imogen was diagnosed as having ASD at 16 years old, despite her mother's ongoing concerns about her health and development since her pre-school years. Imogen's mother discussed her frustration about the delay in securing a diagnosis and the impact of not accessing disability services at an earlier age:

> *I knew Imogen had Asperger's from two… It's been left so long mental health issues have crept in and this is what makes me so bitter… If they had of listened to me, my child would have been helped sooner and she wouldn't be as bad as what she is now… She would have had a therapy in place* (Imogen's mother).

Dawn's former foster carer suspected that her intellectual disability could be the result of her mother's alcohol misuse but felt there was a reluctance to diagnose foetal alcohol syndrome, despite her ongoing challenging behaviours:

> *Dawn was very, very needy and she would punch you to get attention… I reckon Dawn has foetal alcohol syndrome but… no-one wants to diagnose that because there is no treatment for it* (Dawn's foster carer).

For young people with more severe and multiple impairments, impairment affected many aspects of their lives. For example, Declan's mother commented on the impact of ASD and severe intellectual disability on his daily life:

> *Declan couldn't go out himself. He has no sense of danger whatsoever… He has very little verbal communication... He has no awareness of stranger danger. Declan couldn't cook for himself… I would still change his clothes. He would ask for a shower and a bath... He can't read, he can't write... He's really functioning at the level of a three to four year old* (Declan's mother).

Belinda, who had cognitive and physical impairments, also experienced regular epileptic seizures and described how she feels about the effects of impairment and taking medication:

> *My seizures make me fall over… and hurt my skin the way nobody would like to be hurt… It makes my head dizzy, the way it will be badly out of control... and it makes my skin shake all around the outside and the inside of it. And it makes me not know where I am… and it makes me forget who my friends are and who I really am... I don't like having to take so many tablets... and injections... It makes me feel like, why does this happen in the first place? The most thing I feel sad about is having to live with them. And I'm sad that they come back and forwards stuck inside me. And I feel sorry for the staff having to sort them out... and I feel sad when I have to go to hospital to get the illness sorted out... I feel very sorry for myself having to live with an illness in my head.*

In addition to the effects of seizures and medication, Belinda's mother commented on how her impairment led to challenging behaviours:

> *Belinda will say no to things even if she wants to do it just because someone else has suggested it or told her to do it… and she has lashed out… She can ostracise people really easily… I don't think she does it to be really bad… She says her brain tells her to do stuff.*

Other young people with less severe levels of impairment gave examples of how their impairment impacted on their lives. For example, Simon who had Asperger's syndrome explained how he needed additional support at school. However, interestingly, he also felt that his intellectual disability was not as 'serious' as having a physical impairment:

> *I do [have a learning disability]. It's not really serious. I just need extra help with my work and stuff and sometimes I get stuck on words... It's not like serious, like where people are in wheelchairs.*

In terms of communication, Simon summed up his understanding of his memory difficulties and the strategies he uses to help him retain information:

> *Whenever I was younger I lost a bit of my brain cell… and that means I forget things very quickly... I'd have to have an alarm... or write it on my hand or something to remember it… Whenever something comes in my head I forget some things. And then I make up a story and make it the way I think it's like… I don't like people telling me things on the phone that is important. I'd rather them to text it to me because if I can't read it I show it to someone else I know and they tell me what it means… I hate when people tell me on the phone cos I just forget.*

Simon's carer was concerned that he appeared more able than he actually was and, as a result, his needs could go unnoticed. She expressed her anxiety that professionals were not fully aware of the extent of his vulnerability as he left care and his reluctance to be open about his disability-related needs:

> *Simon thinks he's more capable. The biggest problem is his inability to actually admit that he couldn't do things and that he needed help... He's very easily distracted... Physically, he can do his laundry… but he can then walk away and leave the iron on... An awful lot of it is down to Simon's emotional health at the time… He doesn't realise how vulnerable he* is… *All these new professionals coming into his life don't know Simon. My fear is that… they think he's much more capable, because Simon can talk the talk* (Simon's foster carer).

Several social workers (including Simon's) also highlighted the danger of over-estimating the cognitive abilities of care leavers with intellectual disabilities and the importance of meeting their support needs:

> *Very often Simon may come across as having an understanding of a situation whereas his ability to retain that information and really act on it would be very impaired and it's just trying to not overlook that... Simon will always need someone there for him trying to talk him through situations and issues... He had great difficulty in initially accepting that he had a learning disability... because he wants to have the life that he sees other people having… but he's very aware that he's not always able to do that... Our role is just trying to make him feel confident about the skills that he has... but also then, get him to buy into areas that he needs to have that support with and ways that he can learn to do things* (Simon's social worker).

Social workers also found that some care leavers with Asperger's syndrome found it difficult to accept advice and preferred to learn by their own experience:

> *His Asperger's does affect him… He's very tunnel vision. If he has an idea in his head he will do it regardless of the support or advice that you give him... A lot of times they haven't the capacity to... take on appropriate advice so they will make negative decisions* (Jake's social worker).

David who has ASD preferred to isolate himself from peers and public spaces, spending considerable periods alone. With an awareness that ASD was linked to this urge for introversion, David spoke of how he channelled his energies into activities that required considerable interaction with others:

> *I purposely isolated myself… I like my own company but… I have always challenged myself. I don't like my autism to hold me back… I'm an ambassador for [a local charity]... I have done lots of stuff that is challenging.*

Whilst some care leavers could clearly articulate their impairment experience, often explaining impairment as just part of who they are or their daily life 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 she experienced in group care settings, she also found it difficult to accept the diagnosis. She felt that, due to her diagnosis, professionals held negative, 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 people's facial expressions'... There was never a positive.*

Her social worker explained the challenges for Imogen as she attempted to understand her impairment and its impact on her entry to care and social communication:

> *It's been difficult for her because she's been told 'You know you have this condition and that's not your fault' but she's the one who's removed from the family so it's like a contradiction... She finds it so difficult just to understand the most basic of conversation in situations... Just not understanding people's humour and that really gets to her... She just doesn't feel like she fits in... And once Imogen has an idea or a thought in her head, that's it, she's very fixated on it so you couldn't even sort of sit and unpick it... She won't even listen to you really. I think that's just been massive struggle for her* (Imogen's social worker).

Similarly, David was reluctant to identify with being a disabled person:

> *I hate the thought of it but unfortunately I do see myself as someone with a disability… and it annoys me to say it.*

David's PA was aware of David's desire to feel the same as non-disabled people in society and sought to promote his independence whilst also offering support when needed:

> *We knew that he would try to manage things himself first… cos that's what people do and David only wanted to be normal... so there was still a need for him to be an independent adult… We had a good enough relationship in that if there was anything untoward he would come to us* (David's PA).

Similarly, another social worker commented on how she focused on the young person rather than their impairment label:

> *Every young person is unique without a doubt and if they have a diagnosis then that's another level of individuality... but it's just about working with those people who have known them already like their foster carers and learning form them what ways work and also being open minded to what the young person is saying to you* (Susan's social worker).

Some social workers adapted their approach to working with disabled young people to offer them more control and to develop a trust-based relationship:

> *Everything's black and white with him... It takes him so long to build up that trust and relationship with someone... He has to be in control of the situation* (Danny's social worker).
>
> *With the Asperger's, it's about engaging everything at his level and as much as possible letting him lead his care planning* (Jake's social worker).

Connie's social worker and PA worked closely with her using repetition techniques to enable her to learn how to manage her medical appointments independently. In another example, Susan's social worker also explained how she was working with Susan to find ways to engage which were less paternalistic:

> *Because of her learning difficulty I'm always conscious that she doesn't necessarily understand what I am saying. She's very accomplished at giving you the impression that she does understand and... she hates me saying 'Do you understand?'... 'Cos it makes her feel like everyone thinks she is stupid... I'm trying to say to her... 'I ask this of all my young people cos it's part of my job'... That it's not just about her… We have talked that out... She's going to think of another way that I can ask that question* (Susan's social worker).

Whilst the young people above showed insight into their diagnosis and experience of impairment, others reported having little information about their condition. For example, Jake did not feel he was disabled and told researchers he had not been given any information regarding his Asperger's diagnosis and had 'googled it once' to discover for himself facts about the condition.

Furthermore, some young people did not accept their diagnosis as they experienced little or no impairment effects. Interestingly, a couple of these young people highlighted that it could still be useful to have a diagnosis in order to be given special consideration. For example, although Jake disagreed with his diagnosis, he explained how his disability was put forward during court appearances as mitigating evidence in defence of criminal behaviour. Similarly, Simon explained how he had, on occasion, taken advantage of his diagnosis to explain forgetfulness to other people:

> *I don't know what it is exactly... I used to use it... as an excuse, cos sometimes I forget... 'It's not my fault, I've a learning disability'. I would use that.*

However, Jack, who had a diagnosis of Asperger's syndrome, had stopped identifying himself as being disabled as he felt that disclosure of disability often resulted in the inconvenience of explaining his impairment to others and countering professional assumptions that he required additional support:

> *I don't usually put it [Asperger's] down on the paperwork… because it doesn't really affect me. It is mild… I suppose when it comes to Tech, if you say you have Asperger's they automatically assume that you need support… It has happened to me a few times so I have stopped putting it down because I couldn't be bothered with them arranging meetings and wasting my half hour trying to get information out of me and me going 'I don't want support… When I want support I will come to you'.*

Jack's social worker noted how his impairment impacted on his behaviour and indicated that he may not fully accept his diagnosis. However, he also noted that limited efforts had been made to engage with Jack with regard to his experience of Asperger's syndrome:

> *He acknowledges his Asperger's but I think he doesn't truly accept it because I don't think a lot of work has been done with him... He will lose his temper very quickly but, like a lot of the Asperger's young people, it changes almost immediately... He might come on the phone really angry and swear away but the next day it's as if it never happened. It just goes over the top of his head* (Jack's social worker).

Social workers reflected on the challenges of working with young people who disassociated from disability labels and services but still had a range of ongoing support needs:

> *Where young people don't want to recognise their disability that can be difficult... It feels like a label they don't want and it's how we work with young people without them feeling labelled and how you strike that balance about allowing them to make decisions about their own lives in a safe way* (Charlie's social worker).
>
> *The big one is the young people not feeling they have a learning disability. They may feel that it is just because of the over-scrutinisation they have experienced whilst in residential care. Because you have got 20 sets of eyes on you focusing on every one of your characteristics and mannerisms, that increases the likelihood for diagnosis. The young person may in their own views not feel that they have it. They will actively resist those referrals* (Connie's social worker).

Alana was also keen not to disclose her diagnosis of an intellectual disability, explaining how she relied on her mother for assistance with reading and refused disability services:

> Interviewer: Do you have a disability?
> *I do. I don't know [what it's called]… you would have to ask my mummy. But I can hardly read and I cannot write properly... I can write text but the boyfriend doesn't know anything about this... If I get post, I hand it to my mummy. I can write text… So just day to day stuff. 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. I don't want anybody else knowing* (Alana).

In addition to impairment experiences, some young people highlighted their experience of disabling barriers in society. For example, some care leavers with intellectual disabilities experienced low expectations with regard to their future potential to secure employment. In such situations, care leavers had to work hard to counter negative assumptions about their inabilities or need for support, as Dawn explained:

> *My foster mum always says to me I won't be able to get a job unless I have a lot of help beside me. That's the way she sees it with my special needs… I've done work experience and I have always had the help but not always beside me… I would have been fine with that… I got there.*

Care leavers also encountered negative social attitudes towards disability and experienced social exclusion or bullying because of their impairment. Dawn particularly felt assumptions tended to be made by people who did not know her well:

> *It is probably outsiders mostly that don't know the person. If the person with the disability sees that person staring at them… or talking about them it affects them and how they're feeling. If they were feeling good about themselves saying 'I'm doing this and trying myself', that could put them down. I've had that as well but you just learn. You just let it go over your head because you don't know them people. It doesn't matter.*

Such disabling experiences impacted on how care leavers understood their impairment and, for some, denial of their impairment was a self-protection strategy. For example, Danny, who has autism and ADHD, explained how he had tried to hide his diagnosis to stay safe:

> *I didn't even know until I was late 16… I have a mixture of both ADHD and autism... After I was diagnosed people were saying 'Oh I knew that's what Danny had'… I was trying to keep it a bit of a secret... Everybody knew then that became the brand new reason to bully me.*

Danny, like many other young people in our study, had multiple experiences of disablist bullying, both at school and in the community. These issues relating to social isolation and bullying will be further explored later in the report.

SUMMARY

Some young people had diagnosed mental illnesses and several had experience of self-harm and suicidality. Some of these young people were in contact with specialist mental health services, however, several were not receiving specialist support despite ongoing mental health needs. Young people who had previously lived in foster care placements tended to continue to avail of informal support from former carers who still provided an important source of emotional support.

Care leavers who had been diagnosed as having an intellectual disability or ASD described their experiences of impairment and the negative impact of disablist attitudes on their daily lives. Some were reluctant to engage with impairment labels or disability services due to stigma or paternalistic approaches. Young people valued partnership-based approaches and social workers who offered them more control of decisions, focusing on their capabilities rather than assuming incapacity.

3.2 CARE PATHWAYS

The focus of this study is on the experience of leaving care. However, it was also important to offer an opportunity for care leavers to draw connections to their earlier experiences of coming into care and living in various care settings as these experiences set the context for leaving care. This section explores young people's reflections on coming into care, their care experiences and the informal support they had access to during this time.

3.2.1 Pre-care Experiences

Age of first entry into care for the case study participants ranged from birth to 17 years. Most of those who had come into care at older ages could offer a clear understanding of circumstances that lead them into care, most commonly neglect:

> *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).

Neglect in terms of lack of food or a suitable living environment was often in addition to other experiences of abuse. Young people gave several accounts of emotional and physical abuse. For some, witnessing domestic violence was also a routine feature of family life. Jamie's memory of futile attempts as a young boy to defend his mother from domestic violence remains vivid:

> *There was this one man and… they were drinking together… He started hitting her… as a child you don't really want to see that… I remember trying to kick him in the back of the head. Obviously I wasn't helping but I thought I was back then, with my wee foot.*

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:

> *Mum had mental health problems... and dad was an alcoholic and was a gambler and would disappear for days… In the end, mum had a nervous breakdown and then once mum left, dad couldn't cope so dad drank even more and then we ended up being taken into care* (Lorna).

> *It was really difficult... I wasn't getting treated well... I wasn't getting really fed that well and I wasn't getting washed well and stuff, 'cos it was hard for mum cause she's a learning disability.*

Some young people recalled pre-care childhoods characterised by a lack of routine and boundaries. Jamie, for example, described how a lack of parental guidance led to his anti-social behaviour and subsequent contact with police:

> *We were allowed to go out and do basically whatever we wanted. We would go out in the morning and we wouldn't come back until night time… Obviously I was doing bad stuff, throwing stones at people's cars, breaking their windows… and there was always police at the door, but I never had anybody to tell me that was wrong.*

Similarly, Chloe recalled the impact of neglect and how her siblings helped to care for each other:

> *My dad left when I was wee and my mum's an alcoholic… My brothers would have looked after me. They would have stole food from the shop and then I would make dinner* (Chloe).

As care leavers were negotiating their sense of identity and family connection as they left care, there were ongoing issues as they tried to understand the reasons why they were removed from their birth families. For example, although Tony was admitted to care due to emotional abuse and neglect, his social worker explained how he still revisited the reasons for being removed from his parents' care feeling a sense of guilt related to his own behaviours:

> *There are things from his childhood and his time with coming into care which... affect him... That has fluctuated over the years where at times he has been very keen to go back over it... That will always remain with him under the surface to some extent but I'm not altogether sure if he'll ever get the answers that he's looking for* (Tony's social worker).

Louise's social worker also explained how the memory of familial abuse impacted on the type of care placement she needed, and made it difficult for her to settle in family-based care:

> *She went to the foster carer's house but she couldn't cope with it... It reminded her of a house she'd lived in when she'd been abused. It traumatised her.*

Young people who experienced a lack of parental direction and supervision sometimes presented with more challenging behaviours as they grew older, particularly on reaching adolescence. Some participants remembered being increasingly beyond parental control, recalling explosive and often violent rows with parents and other family members. These situations, sometimes involving police, could result in young people's admission to care. For example, Imogen came into care following a series of episodes of violence against her mother and siblings in the family home:

> *There was a lot of build up before Imogen went into care. She was very violent towards myself. It just spiralled out of control… The police were at the house every day due to it* (Imogen's mother).

Danny, who had suffered neglect and physical abuse, also became aggressive towards his mother as he grew older. However, Danny was angry about being removed from his family home and felt a sense of injustice about this experience, as his former carer explained:

> *It got to a point where he got bigger than his mum and… he realised that he could hit back. So now his mum became the victim… So they took them out of the household… He came in with the [perspective] like… 'All that bad stuff was happening to me and they did nothing about it. Now because I hit back at my mum… I get carted off'* (Danny's foster carer).

For young people with multiple or severe impairments who presented with increasingly challenging and violent behaviours, their entry to care was due to a breakdown in parental capacity to manage behaviours at home or risks to themselves or others in the family home. Paul's mother recalled the build-up to his admission care:

> *His behaviour became so disruptive that we voluntarily withdrew shall we say before he killed somebody… We were in crisis… The whole family really was going into meltdown* (Paul's mother).

Similarly, Declan's mother described a similar deterioration in behaviour prior to his entry into care and how, as well as directing aggression on himself, he targeted her:

> *When Declan hit puberty… any problems he had were magnified… He was actually quite hard on himself as well. He would have banged his head off walls, banged his head off pictures… Then when puberty kicked in… I was his target… I got the full brunt of it… I would have been bleeding most days. His father would have had to try and get him off me… Then whenever this red mist would have come down… it would have been 'Declan's sorry, Declan loves his Mummy'* (Declan's mother).

Declan’s social worker explained how, although his family found it difficult to admit they were not coping at home and reluctantly agreed to his admission to hospital, they now realised this decision was in the best interests of both Declan and their family:

> *His behaviours were escalating... He had to be suspended from school and then was at home on a permanent basis. His parents... wanted to hide a lot of the behaviours because they felt it was... a fault on their part... He would have always attacked his mum... It got to the point that one of the nurses called unannounced and... the family knew then that we knew so we were able to make an application to X [specialist hospital]... and that was quite a difficult time... It definitely wasn’t easy for them... Now the relationship we have with the parents is fine... Their life has totally changed. Their relationship with him has totally changed and all for the positive... They don’t know how they did it and none of us know how they did it in terms of the abuse that they put up with and it wasn’t his fault. It was just his way of communicating and mental health deteriorating* (Declan’s social worker).

Memories of Coming into Care

Participants who were old enough to remember the day they came into care often had clear memories of this event. Some, like David, recalled how distressing this experience was:

> *Going into care was probably a traumatic experience probably down to my own actions going in.… The whole fighting attitude of not wanting to go into care at the time.*

Chloe remembered how her mother had agreed to her admission to care, following police intervention:

> *The police and all had to take us out of the house… You know the way the parents would say 'no you can't take them they're my kids'. My mum said 'I'll help you pack their bags'… She was drunk.*

Laura recalled the circumstances on the days and weeks leading up to her being taken into care:

> *My dad was in jail and my mum was an alcoholic... She left us all in the house by ourselves for two weeks and didn't come back so we just got lifted... We were walking about the street in our nighties.*

Young people described feeling ‘scared’, ‘worried’ and ‘upset’ when they were first taken into care. Despite having suffered neglect or abuse at home, many remembered desperately missing their parents. Additionally, young people experienced sadness at being separated from siblings. In contrast, those who were placed with siblings remembered a sense of relief, like Sam, who took comfort from being able to remain with at least one sibling:

> *It was a bad life with mum and dad… Someone just took me in a car and me and my brothers were separated and just led into cars … At least I had one brother with me so I was happy.*

Although later reflecting on positive experiences of residential care, one young person likened arriving at a children’s home to beginning a prison sentence:

> *When I first went into residential care it was completely difficult… The social worker has 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* (David).

Although young people described a sense of loss and trauma associated with coming into care, they also acknowledged the positive experience of moving to a new home offering adequate parental care:

> *It was bad not being with your biological mum but it was good in a way because there was actually somebody else there to pick you up and be like your motherly figure* (Jamie).

Support from Extended Family or Friends

Most young people had varying degrees of support from extended family members. These relatives provided emergency or short term care until more permanent arrangements could be made, sometimes supporting efforts for young people to return to their birth parents. However, young people were more likely to go back and forward from home to extended family members a number of times before eventually going into care on a more permanent basis.

Before and after entry to care, young people recalled numerous examples of practical and emotional support from wider family networks. For example, Jamie commented positively on how his uncle regularly called at their home to provide support and intervene to protect him from ongoing domestic violence in the home:

> *He was always there to look after me... He was great… He came around that night… and he seen him doing this [domestic violence towards mum]. So he got him out and stuff, phoned the police and I would say that pushed social workers more to get us out.*

Jamie’s uncle was a positive role model which was a feature of many of the young people's stories of key extended family members who supported and mentored them at various stages of their lives:

> *He sat me down one day whenever I was... having bother in school. He just said to me ‘Look I used to have the same problems you used to have. I got kicked out of school’... He had no support and he had to go out and get his own wee place and he had nothing in it... He went and got a job and worked his way up... He’s been there… So I kind of look up to him. That’s why I’m trying to build my life up as much as I can. I just want to make him proud in a way* (Jamie).

During their time in care, some young people continued to receive support from aunts, uncles and grandparents. For example, Tina described her grandparents as a constant source of support:

> *I speak to my nanny every night… They were a big part of my life and I was like their special grandchild* (Tina).

Some young people also availed of support from friends, particularly those who went into care in their teenage years. For example, Tony, after being removed from the family home by police, stayed temporarily with friends between a brief period of homelessness and placement in foster care.

SUMMARY

The findings presented above provide insight into how care leavers remember their life before care and their feelings and experiences as they came into care. Their recollections of neglect, abuse or abandonment highlight prior negative experiences of parenting which continue to impact on their lives as they leave care and on their relationships with their birth parents, a theme that will be further explored later in the report. It is also important to note the importance of informal supports from extended family members who were significant sources of practical and emotional support for children and young people before and after their full-time entry to care.

3.2.2 Kinship and Non-relative Foster Care

Nine young people in the case study sample had experienced kinship foster care, mostly with aunts, uncles or grandparents. However on a few occasions young people were looked after by older siblings. 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. For example, Joanne lived for a short time with her grandmother while her mother recovered from a period of mental illness. However, Joanne's case also highlighted the dangers of relying on family members to assume caring roles without a robust assessment of risk and caring capacity. Joanne's relationship with her grandmother was acrimonious and her capacity to provide adequate care was compromised by substance misuse:

> *Me and her just clashed… She was addicted to prescription medicines... and never bothered with us* (Joanne).

Others remained on a longer term basis with their kinship carers and described positive experiences and strong relationships with their carers:

> *They're my parents... It's little things like my uncle taught me how to ride my bike and when I fell off my bike, he picked me up and told me it would be alright... They've just been there all the years and I adore them... I just couldn't cope if they weren't here* (Lorna).

Social workers were very positive about kinship foster care and the connections it offered to wider birth family relationships. However, reflecting Joanne's experience, they held concerns about some caring arrangements within families. Linda, for example, was living at home on a Care Order and her social worker was concerned about the family's over-reliance on her sister to assume the main caring role.

In some kinship care cases, young people had initially found it difficult to adjust to kinship care especially when they were older:

> *It was like a whole different lifestyle… She [kinship carer] was very wealthy… very strict* (Norah).

Kinship care arrangements could also fracture relationships within the family and with social services. For example, Norah's social worker explained how her mother's dissatisfaction with her kinship care placement led to a complete disengagement from social services:

> *Mum didn't want anything to do with social services. She felt that social services were nearly to blame for the fact that Norah was in care and she... would have preferred her to have been cared for by a stranger.*

However, for most, kinship carers often played continuing supportive roles when young people left their care. For example, Alana was placed in the kinship care of her aunt who continued to provide support and assistance when she returned to live with her mother at 18. Alana's mother discussed the ongoing reciprocal supportive relationships within their extended family network:

> *We are a very close family… She is more than welcome to go over to her aunt's… She reared mine for a couple of years but I looked after her grandchildren every now and again* (Alana's mother).

Whilst kinship care offered many benefits for those living in such placements, the most common family-based care setting was non-relative foster care. More than two thirds of the participants (n=22) had experienced one or more non-relative foster placements. Reflecting experiences of kinship care, young people had mixed experiences of non-relative foster care.

Rick and Anna, who both had intellectual disabilities, had lived in their non-relative foster placements since they were young children and were fully integrated members of their foster families and their extended family networks. At the time of the study, Rick and Anna were living in these placements under the GEM Scheme and both were assured they could stay with their foster families for as long as they wished. Prior to these long-term placements, both Rick and Anna were in non-relative foster placements where their needs were not being met. Although they were unable to remember these earlier placements, their foster carers were able to give some insight into difficulties associated with their previous placements:

> *He'd been neglected by the foster carers... He couldn't read, he couldn't write... He didn't know what his name was… He was in a very, very poor state of health and presentation when he came here… very badly presented. His dental treatment needed done… he hadn't been to the optician and just it was a pity* (Rick's former carer).

Several young people could remember their time in non-relative foster care settings as unhappy periods in their lives when they had experienced further abuse or neglect, as Sara recalled:

> *She wasn't really good to us. She would pretend that we were sick all the time and locked us in our rooms and all and social workers figured it out so moved us… She was horrible.*

However, there were many positive examples of non-relative foster placements in which young people enjoyed safe and secure environments and developed close relationships with foster carers and foster siblings. After Sam's first placement broke down, he moved to his second non-relative foster placement where he reported feeling happy:

> *I had a really brilliant relationship with X [carer]. We used to go out all the time and do cinema and it was a good relationship* (Sam).

It was evident that many foster carers cared deeply about the young person in their care and made great efforts to provide support and accommodation for them. For example, Dawn's former carer quickly adapted her living arrangements to avoid Dawn's intake to a children's residential home:

> *I was asked to take her and I was living in a flat… I didn't have a bedroom for her. And they said 'We are going to have to put this wee girl into a children's home'. And I thought I could put a bed there under the stairs… and it would do for a couple of weeks… and it did* (Dawn's foster carer).

Some participants struggled to adjust to structured boundaries in non-relative foster placements, perhaps reflecting the lack of structure in their lives before entry to care. For example, while Simon appreciated the care he received from his non-relative foster carers, he disagreed with some rules and conflicted with other young people living in the home.

> *When I came here they made me, like, I was one of their children... She's [foster mother] very helpful and she's went through a lot for me… [but] sometimes this house annoys me… Like, whenever I'm going on PlayStation and they're busy saying no... I used to have an Xbox down in my room but she stopped it cos I was… not going to sleep.*

Another young person described a positive experience of non-relative foster care but ultimately, her desire to return to her birth family home to join her siblings led to a breakdown in her placement and she returned home:

> *They were good like, but, it's just the fact I think you want to be with your mummy... We were spoiled rotten up there... It was brilliant, I liked it… Then we got to about 16… All my brothers and*

> *sisters were home, and then I wanted to get home... They actually allowed me to stay home with mummy then because I was old enough* (Sara).

Young people also highlighted the complexities of relationships with carers as they dealt with their emotional reactions to being in care. For example, Tony positively appraised his non-relative foster placement but felt remorseful at disclosing inaccurate information about his birth parents to his carer which had negative consequences:

> *He [foster carer] was a very nice guy but… he didn't understand how the system worked… Certain things that I had told him, that he had told social services had a very detrimental effect on my mother… Being a child that's extremely confused and very pissed off at everyone you can say things that are completely incorrect and that would be something that I would hold against myself for quite a long time now* (Tony).

Most non-relative carers did their best to meet the emotional and physical needs of the young people in their care. However, in some cases, family-based care was not suitable, particularly for adolescents. David, a young person with ASD, explained why he preferred a residential placement as he found the adjustment to foster care challenging:

> *Initially I was put into a foster home for a couple of nights... I don't like the idea of going into a false family situation. I had a family, you know what I mean? ...I just didn't get the whole family thing. For me… the children's home was a better option.*

Family-based care was also not appropriate for some young people with ongoing mental health needs. For example, Louise's social worker explained how, despite plans to offer a non-relative foster care placement, she remained in hospital care:

> *There had been a foster carer identified.... She engaged really well with the foster carer who was very committed to it and was very good to her... It was all very positive... But she couldn't cope with it... She made it clear to me that she really liked the foster carer but she couldn't live with her... It was just purely about a family setting* (Louise's social worker).

Johnny's social worker commented on how some non-relative foster carers viewed their role as a 'job'. He knew that Johnny's foster carers were not willing to extend the placement beyond his 18th birthday and felt there was an inevitable detachment as the placement neared an end:

> *His carers are very nice people but… they also have to maintain some kind of detachment... And that's obvious to Johnny and it's obvious to us… I'm not saying it's just a job but that's what fostering is for a lot of people.*

In addition, a breakdown in carer relationships within foster families could also present difficulties for young people in foster care, as one social worker explained:

> *There was a lot going on in his foster placement... He moved out because of the relationship with the foster father... but the relationship he had with his foster mother was excellent* (Jamie's social worker).

3.2.3 Residential Care

Overall, half (n=15) of the young people 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 and hospitals.

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. Joanne, a young person with complex mental health needs and a history of previous suicide attempts, had mixed views of living in residential care. She recollected feeling frightened and unsettled as she adjusted to living in a communal setting 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... all the time and there was no time for thinking or space... I would have been one for locking myself in my room [at home] for hours on end and just listening to music. Whenever you went in there you couldn't do that because you weren't allowed to like sit in a room locked in… There was always kids running about and there was no down time... where you just sat by yourself* (Joanne).

Despite these negative aspects of living in a children's home, Joanne appreciated the structure residential settings provided, after little routine or boundaries in her pre-care life. She also developed close relationships with some staff members and had maintained contact with them since moving on:

> *You went from not even eating dinner with your family to having to sit around a dining room table with eight other people just to get your tea. Or else you weren't allowed to eat… I still talk to social workers that looked after me [there]. I go up to their house and have dinner with them and their family. I was very close to a lot of them.*

There were also other positive memories of residential care. For example, Connie, a young person with a mild intellectual disability and severe mental health needs, stated:

> *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.*

Although Joel experienced several moves whilst in care, his memory of his time in residential care was also positive overall:

> *I enjoyed it. I had my ups and downs… but I can't say the staff were bad… Some of the staff were nice... genuine… and then there were some you knew were just there for the sake of being there.*

Staff and group dynamics were a key aspect of residential care. For example, David recalled his initial uncertainty on first moving to a children's home and how he asserted himself with other young people living there:

> *When I first went into residential care it was completely difficult… but in a way it was beneficial for me. I was able to build up my resilience to different factors that I had an issue dealing with… There was people who would say smart things to try to annoy you. For example, there was one guy who... got up to hit me… I defended myself against that… Everyone realised 'Well he's not someone to mess with'. It's that willingness to stand up for yourself and not just take all the crap.*

At the time of the first interview Imogen, who has ASD and mental health needs, was very unhappy living in a children's residential home due to the staff approach and disruptive group dynamics:

> *Ever since I moved in I've hated it… The staff change... and just don't have time for you… I don't want people telling me what I can't do… and do this and that. I can do it myself.*

Young people, like Imogen, who needed a stable routine and quietness struggled to cope with staff and peer dynamics in a group home and volatile behaviours from other residents.

In addition, residential care did not always prepare young people for the transition to adult life as young people became dependent on staff to maintain high standards of housekeeping and hygiene. Social workers also indicated that young people placed in residential care had a more abrupt transition from care on their 18th birthdays which will be further explored in the next section of the report on leaving care.

Intensive Support and Secure Care Settings

Four young people in the case study sample had experience of secure care settings. Connie had spent much of her care history undergoing several moves between children's residential homes, secure care and intensive support placements. She noted how differences in the structure of various placements had a direct impact on her mental health and behaviour, with more positive outcomes when strong boundaries and routines were in place, as she explained:

> *I used to love going in there [secure care]... I overdosed... the night before [I had to leave]. It was weird. You wanted out but you stayed in. I think it was because it was routine... I had a routine set and then whenever out then I would have f***ed up again and got back in.*

Connie's PA noted how her mental health and behaviour settled while she was in secure care and deteriorated again when the placement was due to end:

> *Secure care had firm guidelines… Everything was clear, and she really thrived. She used to actually throw a wobbler when it was time to get out* (Connie's PA).

Social workers who were working with young people who moved frequently to secure care placements commented on how familiarity with staff in such settings offered a secure and responsive approach. In Susan's case, her social worker explained:

> *It's always really a negative thing when a young person ends up in secure because there are serious high levels of risk but at the same time it gives her a chance... It stops her getting access to substances... and she has good relationships with the staff... who can help de-escalate the situation for her... Her ability to maintain relationships is a big positive for her.*

Specialist Residential Care

Three young people had spent time in specialist residential care facilities for disabled children with complex needs or challenging behaviours and all three, on reaching the age of 18, moved to specialist adult disability residential homes. Both Declan and Belinda had moved to adult residential settings that were expected to be ongoing. Declan's key worker felt his residential placement was the best one available to meet his care needs with close proximity to family:

> *This placement was probably the most suitable because of the level of staffing and their training and their ability to deal with his behaviours… and it's quite near to where his family live.*

Belinda, who has severe intellectual disabilities, lived in residential settings for children with intellectual disabilities during her time in care and was transferred to an adult residential facility for disabled adults at 18. Paul, who has a severe intellectual disability and ASD, lived in a therapeutic community and his mother described the range of activities offered to him as part of his placement in a specialist residential pilot programme for young adults within this community:

> *The young adult residential part of it is a pilot… They are really very unrestricted. There's lots of forest work they can do… it's really fantastic. You never get bored and they can go off and do all sorts of things* (Paul's mother).

Paul's social worker also commented on the individually tailored support provided by the staff team:

> *Paul has made real progress in all areas of his development... You have the staff team there to support him... Staff understand the disability... It's all taken at the young person's pace... even the structure of his day and his routine... It's about meeting their needs* (Paul's social worker).

Psychiatric placements accommodated young people who had acute mental health needs. Overall, 12 of the young people had experience of psychiatric in-patient hospital care, often in relation to risk of suicide or eating disorders. Some hospital settings were recalled by young people as frightening, even dangerous environments. For example, Laura recalled a traumatic incident in a psychiatric hospital when, at the age of 15, she was physically assaulted another patient who was having a psychotic episode. However, Louise, who had spent all of her care experience in a psychiatric hospital, was positive about her experiences of psychiatric care in both a child and adult psychiatric hospital:

> *For a lot of people it's [child psychiatric ward] really scary but for me anything was better than what I was used to... For me, normal things like... someone looking after you and you weren't alone all the time, those things just meant the world to me at the time so there was a lot of positivity... Although it was a really long hard process like but I got there in the end... Y [adult psychiatric hospital] was a very scary that place [but] it was kind of like a wee haven for me… The idea of moving for me was terrifying at the time... but obviously there was no other choice… Then it did become somewhere I could get used to… There was always someone there and then I had a psychologist and she was really good.*

3.2.4 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. Young people with severe mental health needs, particularly those who had co-existing intellectual disabilities, tended to move placements most often.

Susan, who entered care as an adolescent with an intellectual disability, history of self-harm and substance misuse had undergone a minimum of 12 placement changes in her three years of being in care. Likewise, Connie, who has a mild intellectual disability and severe mental health needs underwent 16 placement changes. Jake, a young person with ASD, also experienced multiple placement changes, including non-relative foster care, children's residential homes and juvenile justice centres. Although some moves were unrelated to the needs of the young people (for example, carer illness or closure of a residential home), many were linked to issues such as young people's behaviour or mental ill health. For example, Laura described feeling confused by placement changes and indicated that she needed more specialist carers who could cope with her particular needs and help her to manage challenging behaviours:

> *When I was in foster placements, they were only for about five six months at a time… I was constantly being moved… shipped from home to home... 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… I used to feel like the odd one out... I always felt like nobody*

> *gave me attention so my only way of getting somebody's attention was to act out… I had behavioural problems… I'd have smashed things, hit out at other people just to get attention. It was my only way of being able to tell somebody there was something wrong… I was very hard to deal with... I think it was more of a matter of trying to find somebody who could cope with me being like that* (Laura).

Lorna also experienced placement breakdown due to challenging behaviours. Her former kinship carer explained how the placement ended as she was no longer able to cope with her escalating challenging behaviours:

> *I just couldn't look after her anymore. Lorna was getting big… She was being very violent and aggressive to everybody constantly. So I had to make the decision for the safety of the other kids as well… We couldn't do it anymore.*

Lorna also described this move and understood her carer's inability to cope in the context of caring for other children in the home:

> *I had behavioural problems and stuff when I was a child. I was very hard to deal with... She couldn't cope because she had [other] children plus her own life to deal with.*

Experiencing numerous placements, however, had a negative and lasting effect on young people's behaviour, ability to trust others and form or maintain personal relationships. Young people described feeling confused by placement changes and, as a result of placement moves, had also experienced school changes and a loss of friendships (further discussed in the chapter on social networks). For example, Jake recalled the impact of the sudden loss of his network of friends when a foster placement broke down and he was moved to a different town:

> *I left my foster place when I was about 12… and I didn't get to say goodbye to any of my mates or anyone I went to school with or anything. I just had to start this completely new life.*

Joanne also experienced changes in peer relationships whilst living in a children's home due to the constant turnover of other young people and staff which limited her ability to form and maintain 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).

3.2.5 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 a quarter of these young people (n=5) were diagnosed on entry to care (four with a mental health condition and one with an intellectual disability).

Mental health needs and 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 care where they had access to intensive support and supervision by highly trained staff. For example, admission to psychiatric assessment units or long-stay psychiatric placements in response to suicide attempts. For those with severe impairments and challenging behaviours, specialist residential placements provided individualised secure care with a high level of staffing to meet their multifaceted needs, as Declan's social worker explained:

> *Declan has very challenging behaviour... He required an ongoing significant level of care that his parents couldn't give him... He'd require the high level of staff. He needed to be in a secure unit. All of those things which a natural family home environment just can't offer*.

For young people who did not require psychiatric or specialist residential care but had high levels of ongoing need, social workers commented on the benefits of specialist non-relative foster placements with carers who could meet their complex needs, however, the availability of these placements was limited.

Secondly, young people's mental health and/or 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. For example, Sam, who had a diagnosis of ADHD and severe intellectual disability, had been cared for in three separate foster placements. Sam often experienced episodes of escalated distress and challenging behaviours which presented risks to other young people in the care setting and necessitated his final transition to a foster placement where he was the only young person living in the home.

Thirdly, impairment effects could be exacerbated in some care settings where their needs were not well met, particularly 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:

> *Because of my ASD, I don't really like all this noise 'cos I can't control this... 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'* (Imogen).

Imogen's social worker indicated that, due to a very late ASD diagnosis, she had not accessed necessary support and had been placed in residential settings that were not best suited to meet her particular needs:

> *It was a real shame that she didn't get the diagnosis until last year because... she's struggled with how she's felt about life and relationships and social situations all these years... The worst of it all being that she's ended up in the care system... There have been different approaches in terms of her care... In her first home they would have a lot more direct work.... She responds very well to that... whereas that hasn't been the approach in X [current home]… They have a lot of bank staff… and the unit was very unsettled... She finds it hard to make sense of that.*

3.2.6 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.

Several care leavers, such as Alana and Sara, had reunited with birth family members on leaving care and had close bonds with their birth parents, as Sara's social worker explained:

> *Although mum had an awful lot of difficulties in her life all her children who had care experience were very loyal to her and she was held in great affection by them. And they all returned to her and they all still live in close proximity to each other.*

In contrast, the majority of participants had strained relationships or no contact with birth parents. Lack of parental commitment to their relationship and unreliability in terms of adhering to contact arrangements left young people feeling let down by parents which took its toll on birth family relationships. Jake was one of the care leavers who felt 'constantly let down' by his mother. For the duration of the study he had no contact with his mother and he had no expectation of the relationship improving due to his mother's failure to change. Similarly, Jamie's foster carer reflected on his experience of contact, his loyalty to his birth mother and her own feelings as she tried to support him through continuous disappointments:

> *He wouldn't have said a bad word even when he came home raging that she didn't turn up for contact... because he couldn't be disloyal to mum… He held it in you see and then acted out… It hurt me like hell to see him hurt. Oh it was awful. I can remember them heading away for contact and me sitting here praying and hoping that she would turn up that day that he wouldn't get a disappointment. Then they moved on to getting his mother to ring about half an hour before to just confirm to lessen the disappointment... So that worked for a wee while and then she just stopped all contact* (Jamie's foster carer).

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 family contact:

> *There's intense contact and then there's nothing... I was able to try… to just get him to understand about her… her illnesses... so I think that helped him... He told me it was the first time anybody has actually sat down and went 'this is what's wrong with your mother. This is why it is the way it is'.*

Jamie developed an understanding of his mother's mental health problems, however, he remained adversely affected by the impact of her mental health on their relationship and still harboured resentment at his life in care:

> *Whenever I was younger I was excited to see my mum obviously but she was... always making up excuses... so I very rarely seen her... Me and my mum don't really get on that well. I obviously hold a grudge at her because I'm in care. She has bipolar and… One time she would be nice to you... saying 'I love you'… and then you just be waiting for the next time she'll say that… She would kick you out very quick if you said the wrong thing too.*

Reflecting Jamie's story, parental ill-health or disability affected contact with birth family for many young people. For example, Sam had a positive relationship with his mother and saw her monthly. However, his mother's poor mental and physical ill health prevented her from visiting him as often as they both would like. Similarly, Rick's mother would regularly cancel scheduled contacts due to her ongoing chronic illness. Parental mental illness that had often contributed to young people's entry to care had an ongoing impact on the quality of contact birth parents:

> *Her mummy doesn't admit to having a mental health problem... That would leave me concerned that she's going to hurt herself or anybody else... But she's very fond of her mummy... She loves*

> *seeing her... We decided to safety map it with the family... so Linda knows how to ring daddy or her sister if she was ever worried about mummy* (Linda's social worker).

Social workers commented on how ill mental health and substance misuse contributed to inconsistent experiences of parenting which impacted on care leavers' self-esteem and sense of identity:

> *The issues for him are his family background and self-esteem... His mum was bipolar and had serious addiction issues and so she has never really been there for him... So no parent who is consistent or giving appropriate support as a child and that has carried right through even now because they still don't support him... He has shut his mum out* (Jake's social worker).

For many care leavers, limited, inconsistent or negative experiences of contact with birth parents left them feeling a sense of rejection. Some social workers also linked these feelings of rejection to poor attachment with birth parents in their earlier years at home and the stigmatisation of the young person within the wider birth family:

> *A lot of the issues are going back to attachment in the initial relationship with primarily mum... There isn't that bond, that attachment... Mum is quite distant... There's this feeling of pure rejection and that is ongoing* (Danny's social worker).

The impact of ongoing difficulties with birth parent contact on care leavers was profound, as Louise's social worker commented:

> *The family walked away and... never made contact again ever... Then last year... she randomly arranged to meet her mum... didn't tell anybody... Her mum… still blamed her for everything... It upset her again... She took an overdose the week after.*

Similarly, Laura's social worker discussed the impact of feeling rejected by her birth parents:

> *Mum will dip in and dip out... and that is a big concern because when she has been rejected before she will take a step backwards to either self-harm… or she will overdose, or she will get involved with an inappropriate group of men* (Laura's social worker).

During the course of the study, David scaled down his contact with his mother who had mental health needs. By the time of the second interview, he required his support worker to accompany him at these times. By the end of the study, David had minimal contact with her due to the enduring negative factors in the relationship which were impacting on his own mental health and wellbeing:

> *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'm not doing anything for her. I barely even ring her… She's a complete nightmare* (David).

As young people left care, some relationships with birth parents were showing improvements, albeit slight in most cases. For example, Joanne indicated that her relationship with her mother temporarily improved after the birth of her child but then reverted to a distant relationship, as before:

> *We got a bit closer whenever I was pregnant and when X [child] was born she was at the hospital but after that it was just like you're on your own again.*

At the beginning of the study Dawn had no contact with her parents and had made the decision to withdraw from her family due to the negative effect contact was having on her mental health. By the final interview, she had met her mother by chance and they had exchanged contact details. Although the lines of communication had somewhat opened, Dawn had not had any further face to face contact with her mother and did not expect their relationship to further develop. However, Diane's relationship with her mother did improve during the course of the study and her mother played a supportive role when she spent time in prison:

> *She's good. She knew what it was all about… She does support me in every way. She was taking charge of my visiting numbers and she had the family coming up and seeing me which I wouldn't have really known to do. I wouldn't have had their number to phone them, so she was there. She was a good support.*

Rick had previously been regularly let down by his mother not attending contact visits but, at the time of the study, he was enjoying a more settled relationship with her. Imogen also enjoyed an improved relationship with her father over the course of the study. At the time of first interview, Imogen had limited contact with her father. However, by the end of the study, she was enjoying twice weekly visits from her father and their relationship continued to improve.

Sam was supported by carers to develop and maintain his relationship with his parents. Their visits had become more regular over the course of the study. By the second interview, Sam was enjoying more positive contact with his parents:

> *The relationship is good. I love my mum... I've been seeing her quite a lot now… It's going well… And dad's there as well… I see them together so it's quite good… We get along very well.*

For some care leavers, space in terms of geographical distance and time for reflection helped create an environment conducive to improved relationships between young people and their birth families. For example, Tony discussed during his second interview how his relationship with his parents had improved following his move away from the family home which lessened tensions in the family:

> *It's just sort of seeing them more and I suppose having a choice to see them... My dad would help me in a lot of respects... I went out for a work placement and I didn't have the money for a bus, so he gave me a lift… or he would throw me a tenner to put electric in the house.*

By his final interview Tony was enjoying supportive relationships with his parents and was rebuilding his relationship with his mother, as his father explained:

> *We see Tony quite often now… We've re-established a lot of contact… Sometimes he can still get a bit aggressive... but, by and large, he's been fantastically helpful. He comes across and helps us so the relationship is largely normalised* (Tony's father).

Similarly, Simon's relationship with his mother also improved over the course of the study. At the first interview, Simon had recently re-established regular contact with his birth mother after a year of very limited contact. However, by the final interview, he had an improved relationship with his mother and no longer required support during contact.

Some care leavers had come to terms with dysfunctional family relationships. With the realisation that family dynamics may never improve to the level they had spent many years wishing for, came a sense of peace. For example, Lorna who had been in care since a young age had accepted, to a degree, that her relationship with her parents would probably never improve beyond its current state:

> *It can be trying at times… We get on sometimes and sometimes we don't. It usually depends on what sort of state their mind is in… I spent nearly 15 years away from my mum and dad so I don't have a fantastic relationship with them anyway. My carers are the parental figures and they [birth parents] would be just outer family… not a nice way to put it but that's the way I would see it... it's never going to be perfect.*

Some young people enjoyed good relationships with one parent despite poor relationships with other family members. For example, Anna had major difficulties in her relationships with her birth mother and siblings but enjoyed a positive relationship with her father. Strained relationships with a step-parent were also cited as another obstacle to contact with birth family. For example, Rick's foster carers supported him to request contact with his mother on her own due to his concerns about joint visits involving her partner.

Several young people indicated that the severity of abuse and neglect were often not fully comprehended by extended family members who sometimes attempted to mediate between care leavers and previously abusive parents. For example, Louise's relationships with extended family became strained due to their well-intended attempts to reconcile her with her parents:

> *It sometimes feels like their loyalties would lie with my parents than they would with me… Their experience of my parents would have been totally different from what I experienced so it's very hard for them to understand what the problems are* (Louise).

In contrast to those who were enjoying improved relationships with birth family, some young people had ended all contact with their birth family as they felt that relationships were irreparable:

> *They are trouble makers. They didn't support me enough… so I haven't been in contact for over a year now with them. It does hurt a bit but… I didn't want them to have any more contact. I told them that was it. I gave them loads of chances. Not a very nice family* (Dawn).

In some cases, parents refused to continue the relationship. For example, Laura's frequent suicide attempts led to a cessation in contact with her parents:

> *They don't talk to me at all anymore… The last time I overdosed my dad told me I didn't do it right. They don't want to see me anymore.*

In contrast to young people who had entered care for reasons of abuse or neglect, those who had been voluntarily admitted to care because their parents could no longer meet their needs or cope with their challenging behaviours often enjoyed ongoing contact with birth parents. For example, Imogen's mother demonstrated a firm commitment to her parenting role:

> *It's my duty, whether Imogen's 18, 38, 58 as her mummy to be there, whether it's good, bad or ugly* (Imogen's mother).

Imogen's social worker described the ongoing role her mother had played:

> *Her mum is very involved... She.. would see a lot of her... She comes to any meetings... and court... Imogen would be on the phone when she's having difficulties in the evenings... and there's times where she has met her to settle her... It is mum's plan that she will have a shared care arrangement because it's such a massive thing for Imogen, that family contact and feeling part of the family* (Imogen's social worker).

All of the young people with severe intellectual disabilities who were living in residential placements had regular family contact. Some enjoyed shared care arrangements. For example, when Paul's behaviours were settled, his parents cared for him at home during weekends and school holidays, although they were not in a position to care for him on a full-time basis at home. However, in some cases, family contact was supported by staff due to risks of challenging behaviour. Transitions to new care placements could also impact on family contact arrangements. For example, when Declan transitioned to a new adult care placement, contact with his parents was reduced temporarily to telephone calls until he settled in his new environment.

Sibling Contact

The majority of care leavers in the case study sample (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, other young people described more mixed or negative sibling dynamics where relationships with siblings were strained and contact was minimal, if at all. Some young people had restricted contact with siblings and other family members due to risk of harm, child protection issues or court proceedings.

Many siblings were separated from each other during the care experience due to lack of suitable joint placements, complexities of care needs or child protection issues. Jamie's experience of separation from his siblings when they were placed in different care settings resulted in a distant relationship with them:

> *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).

However, young people who were placed with at least one sibling on entry into care drew comfort from being with a brother or sister during the often stressful or traumatic events of their removal from the family home. In some cases, siblings were separated after initially being placed together due to an escalation in challenging behaviours:

> *I had one brother with me so I was happy… I had a great life with them, but unfortunately then he left because he was being bad and not a very nice person, so I was sad when he left* (Sam).

Similarly, Laura was initially placed in care with her sister who was subsequently removed, leaving Laura alone in her placement which had a significant impact on her mental health:

> *I overdosed and tried to hang myself and I cut an artery… I think it was because… I missed her a lot… I grew up with her beside me all the time and then one day she was gone. That was really hard.*

For some, leaving care meant a separation from siblings who were living in the same care placement. For example, Simon lived in the same non-relative foster care placement as his brother before he moved into supported living. In contrast, other participants regained contact with siblings when they left care, particularly if they returned home. Some young people were keen to re-establish contact with estranged siblings to explain her perspective on family issues as Anna's social worker explained:

> *She has been keen to meet him [sibling] because I think she felt she needed to get her point across as to what happened... but she was let down again because it never happened… She hasn't had the chance to just resolve any of that in her own head... I think more and more now it's less important to her... She's now realising they're not making efforts* (Anna's social worker).

A breakdown in relationship with birth parents could also block sibling contact, particularly when siblings were still living with their birth parents:

> *Whenever I first moved in here I didn't get seeing my sisters… I hated mum at that stage, absolutely hated her* (Norah).

On this occasion, mediation between Norah and her mother was supported by her 16+ social worker and contact arrangements with her sisters were re-established.

At the time of interview, many young people were separated from siblings geographically as siblings lived in different parts of the country or had moved abroad. Jamie expressed his desire to visit one of his brothers more often than he was able to but was restricted by insufficient finances to cover the cost of public transport:

> *I would be close enough to him. We like the same things… I go up and stay in his house and chill out and talk... It's just whenever I've spare money. It's not too often to be honest but it can't be helped. I would love to visit more if I had the money* (Jamie).

Some young people, particularly those with intellectual disabilities were vulnerable to exploitation from siblings, particularly financial exploitation. For example, Rick, who had a moderate intellectual disability, had been financially exploited by an older sibling.

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 living in out-of-home care:

> *His brother struggled the most in terms of him being in care and... not coming home... Mum and dad... protected his brother from those conversations they were having as a couple and so he... couldn't understand why Declan couldn't come home... A lot of parents and professionals don't realise how much siblings are taking on themselves* (Declan's social worker).

SUMMARY

Young people experienced various types of placements during their time in care. Some young people underwent several placement changes which impacted on their emotional wellbeing and behaviour. Mental health and disability impacted on placement type, placement stability and contact with family. Birth family contact issues highlight the impact of ongoing negative or strained relationships with parents and the lasting effect on their wellbeing as they moved into young adult life. Others had re-engaged with birth families as they moved on from care, although, some young people still required support from carers and social workers to ensure such contact was a positive experience. 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.

3.3 LEAVING CARE

This section explores young people's varied experiences of leaving care and pathway planning. Efforts to prepare young people for leaving care are also discussed, including the role of carers, social workers and schools. The core challenges for young people transitioning from care are also identified, including issues for social workers aiming to support care leavers in the move from care into adult life.

3.3.1 Pathway Planning

Pathway planning is central to driving forward children and young people's journeys from care to adult life. Indeed, only six study participants did not have a pathway plan. Some of these were at the lower age range such as, Johnny who was still in care. However, both Johnny and his carer would have liked transition planning to be underway as he was almost 18 years old by the end of the study. Johnny expected to move into supported living on leaving care but his social worker had not proceeded with transition planning due to concerns that it could destabilise his current placement:

> *The long term plan is supported living… but again we don't broach the subject with him too much because it unnerves him and he gets very anxious because his foster carers were having a very hard time meeting his needs* (Johnny's social worker).

Some other young people did not have a pathway plan due to the difficulty of completing one in the context of unstable mental health, placement change or social work staff turnover. Social workers took the view that when young people were experiencing a crisis or instability, it was often inappropriate to undertake formal pathway planning:

> *We didn't even do pathway plans with her.... because our pathway plans are 'How you want to see yourself when you're 21?'… She couldn't see beyond that... We would have done it informally... talking about it and trying to get out of her what she wanted* (Louise's social worker).

> *It is a pointless exercise to try and sit and do a pathway plan... if they are struggling with their mental health... The priority is getting that young person better* (Joanne's social worker).

Most young people had an understanding of the need for forward planning as they transitioned from care and were aware that decisions relevant to their future were set out in an official pathway plan. Indeed, care leavers described an increasing sense of control over decisions affecting their lives as they aged out of care:

> *I felt like I had more freedom… and I was able to make my own decisions. X [16+ social worker] doesn't dictate everything… I could say whether I agreed with it or not. Or if they were saying something I felt that they had got the wrong idea of it, I would be able to explain it myself. Whereas in the early years… they make all the decisions, whether you liked it or not* (Lorna).

Social workers noted that, due to corporate parenting duties, whilst young people were under 18 and in care the Trust led on decisions with more limited involvement from young people:

> *Unfortunately LAC (Looked After Child) reviews a lot of time, there's like 15 people sitting round a table to talk about this one young person... to make up the care plan. So under 18s, a lot of times, it's out of their hands... They're not pleasant experiences... A lot of them don't want to come... I don't blame them... People are just dissecting your life in front of you* (Jamie's social worker).

> *Sometimes in LAC reviews I'm very conscious our young people are literally just… nodding and agreeing... They are like 'I didn't know what's going on... I feel like everybody's looking at me… it's really embarrassing'… A lot of these more complex young people tend to have more professionals involved with them so they will have more people at their meetings which is further intimidating for them... People are making decisions about their lives and they won't necessarily have a say* (Susan's social worker).

Some social workers indicated that there were few alternative ways to approach LAC reviews as they were a standard statutory procedure whilst others emphasised preparation, advocacy and shorter periods of attendance at reviews were helpful:

> *For a young person who has a learning disability… we try to gauge their wishes and feelings prior to the actual meeting, explain to them a bit about the set-up of it... because it can seem very daunting and overwhelming... The worker might advocate on their behalf or they may get a*

> *VOYPIC representative in or somebody who they trust, you know, to relay their opinion across... or have a young person that only attends for part of the meeting... and we explain what was said and why* (Joanne's social worker).

Social workers agreed with young people that as they moved into 16+ services, particularly when they were no longer subject to LAC procedures at 18, higher levels of participation were evident:

> *After they turn 18, the pathway plan is theirs... their views. You can't sit and write a young person's document, the pathway plan review on your own without them being a part of it* (Jamie's social worker).

> *Whilst they are still looked after there tends to be not much engagement in it... non-attendance at LAC reviews and very little submission to their reviews but as they approach adulthood we are reviewing them by pathway plans and I could count in one hand the amount of people who haven't attended... We work with a young person to try and achieve best outcomes as opposed to telling them what we think is in their best interest. And that sort of partnership approach as opposed to big brother, type of dictatorial approach is definitely what works* (Connie's social worker).

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:

> *I'll not do a pathway plan review unless they're there... They very much have to be at the centre... You can't work with this age group successfully if they don't feel they own it... They're very much goals that they need to set that are achievable for them* (Lorna's social worker).

> *We can devise the most elaborate pathway plans in the world but if it's not something the young person is interested in or willing to buy into it's not going to work* (Lorna's social worker).

A major benefit of participation indicated by social workers was improved outcomes for care leavers:

> *You can make the best plans in the world but if the young person isn't involved in that, it's failed... If you are able to develop that relationship with the young person and involve them in the decision making process then the outcomes again are generally more positive* (Sam's social worker).

> *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... 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).

Involvement in reviews of pathway plans also gave care leavers an opportunity to report on whether professionals had taken action on previously agreed goals, thereby providing a mechanism to make 16+ teams and other service providers more accountable:

> *Essentially you are empowering them to make decisions about their own lives... to take as much responsibility and control over the pathway plan itself... It invariably works better if it's their plan as opposed to our plan... and I would encourage the young person to hold us to account if there is something that we haven't done... We do meet we meet regularly with our young people to look at progressing the pathway plan* (Sam's social worker).

Participation in pathway planning and decisions could also build the 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, young people were not always active participants in the pathway planning process. A few care leavers felt their views were not fully taken into account as they transitioned from care. For example, David felt he was not listened to regarding his pathway plan and, as a result, he felt rushed and ill-prepared for the transition:

> *They handled it badly in a sense, I think it was rushed… They need to obviously listen to the young person… I wasn't asked once in that meeting. Everybody was talking amongst themselves. 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.*

Some care leavers disengaged from planning and review processes as they were not interested in participating in professionally dominated environments where the detail of their lives was subject to discussion:

> *Generally the young person just doesn't want the spotlight on them so they nearly just want the meeting to be over and done with or they just won't attend it... It's so intimidating for them coming into that meeting and all these professionals around the room and the language that they are using and talking about quite private things... Reviewing the last 6 months of your life... and maybe... they went through a really rocky period but they have came out the other side of it and it feels like a lifetime ago but that all has to be talked about* (Susan's social worker).

Indeed, one young person viewed her pathway plan as a means for the professionals in her life to communicate with each other regarding her care:

> *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'... So it's to see what they can do for you* (Chloe).

Whilst Chloe made a written contribution to her pathway plan, she did not feel involved in her pathway meeting which was also dominated by the professionals facilitating it and her carer:

> *You go in and people are talking about you as if they know you and they haven't a clue... Like the Head of Social Services that you've never met in your life is telling you that you're doing this wrong and you have to do better at this and I'm like 'You don't even know me'… Don't make it so professional all the time because that would scare somebody off... Like if somebody had an anxiety illness and they know that there's this big meeting going on about them and people are talking about them, it's going to make you sick knowing that you're being constantly watched… 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).

Social workers were concerned when young people disengaged from formal pathway planning processes:

> *You are empowering them to make decisions about their own lives typically through the pathway planning process... dependant on their willingness to work with us... If they don't that makes that*

> *difficult cos we are still obliged by law to complete a pathway plan... What we do in that circumstance is just put down our recommendations and try to link in with the young person and saying 'Are you happy with that? Is there anything else we can add?'* (Sam's social worker).

Some young people viewed the pathway plan document as patronising and irrelevant. Danny was clear on this point:

> *My straight answer would be to get rid of them… I don't like them because the pathway plans are still very childish… 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'. Didn't go down too well* (Danny).

Social workers also expressed dissatisfaction with the pathway planning documentation in terms of length, repetition and use of patronising cartoon imagery:

> *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.... 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).

> *The pathway planning assessment is very repetitive and very childish. That definitely needs looked at and that whole process definitely needs revamped... It's disrespectful... The whole thing is flexibility and tailoring it to the young people and the pathway plan process is like 15 or 20 pages... You could condense that right down into something more user friendly* (Jake's social worker).

In some cases, pathway planning documents had been reduced in size to make them more accessible for young people:

> *We have recently looked at the pathway plan review and revised it to make it that wee bit easier for the young person to engage with it... It was such a massive document... It's sort of been condensed down so it doesn't look as intimidating and… it makes it that much easier for the young person to have their input into what they feel their needs are* (Susan's social worker).

However, many social workers indicated that pathway plans for care leavers with mental health and/or intellectual disabilities needed to be further adapted to be more accessible and social workers should use their relationship and knowledge of these young people to ensure an appropriate approach to communication:

> *It's just trying to involve them in every aspect of it and breaking it down into a language that they're able to understand and working at their pace... and involving all the important people in their lives in it as far as possible... and trying to sort of have an ownership of it... It's their plan for their life... As far as possible getting their comments and what they feel and where they see themselves... That's very important* (Chloe's social worker).

> *There could be issues for young people with a learning disability... The young person maybe knows what they want to do but has difficulty in getting that across. Again it boils down to the working relationship you have with that young person... You may have to be an advocate in some sense...*

> *It is all about finding that level of communication for that young person and... helping them explore and discuss the options... If they are with a worker who they don't have a good relationship with... they're not even going to listen to begin with* (Joanne's social worker).

> *A pro-forma that's more learning disability friendly around pathway planning would be fantastic as it might make it actually easier to break down the pathway plan and look at the bits that are most important in a way that is easy for the person with a learning disability to follow because it's not designed with a person with a learning disability in mind* (Belinda's social worker).

Some social workers also discussed various approaches for involving care leavers with mental health or intellectual disabilities in plans and decisions affecting their lives including more informal consultations:

> *It's very rare I would sit down with any of the young people with mental health or learning disability and just go through the form. It generally works better if it's done in a more general, informal way. So I would take young people out for a cup of tea and we would chat and... then I would write it up and they would look at it. I would read it to them and that seems to work better... For a young person with Asperger's it's about explaining to make sure they understand what it's about. A lot of the young people aren't interested in just another document... So if you try to do it too prescriptive they wouldn't engage* (Louise's social worker).

> *We are always trying to make sure our work is person centred but there's not really tools there to easily help a young person to do that... A pathway plan with Belinda… had to be done over a period of time... It's just about giving them the opportunity to try and express what their wishes are and trying to make them involved in that so they understand what's happening and that if they do have any anxieties or concerns that they are able to express those and are given a chance to talk them through and reassurance and guidance is given* (Belinda's social worker).

Indeed, for a range of care leavers 16+ social workers adopted a more non-direct style of communication to seek their views and ensure some level of involvement:

> *One of the big difficulties particularly for those with borderline [impairments]… or ASD… 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).

However, such adaptation was not evident across Trusts and social workers indicated a need to use a wider range of approaches to engage care leavers with mental health and/or intellectual disabilities to in pathway planning process, including greater use of adaptive technology. For example, one social worker described a pilot of using technology to assist communication with young people in care and indicated that this would be a very beneficial development for disabled care leavers but had not yet been rolled out to disability teams:

> *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).

Such alternative approaches to communication assisted the development of rapport between social workers and young people and also helped to increase their confidence to participate in decisions affecting their lives. In other cases, care leavers were very confident at expressing their views. For example, Jack was particularly strong minded regarding decisions affecting his life and was very clear about his right to make a complaint and refuse engagement with professionals, including requests for a change of social worker:

> *When you are younger… you have no choice. They don't really listen to you. But you see now, no way, I am 21 years of age… I've no social worker sitting on me saying 'No, you have a Care Order on you, you can't do that'… I insisted my child's social worker was changed… You don't have to sit and take it from them… I've asked my PA to leave my house a few times for the way she has got on… I like that I have my own freedom… It's my choice. I don't have to ask for permission* (Jack).

Social workers also noted the confidence of some care leavers and the extent to which they expected consultation and freedom to make their own choices:

> *You have to consult with him at all times before you make a decision. He's very empowered which is lovely.... but rare that our young people have the confidence to do that* (Jack's social worker).
>
> *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).

Preparation for participation in pathway planning meetings and sharing reports with young people in advance of meetings was an important aspect of enabling young people to play an active role. For example, Imogen's social worker took time to prepare her for planning meetings, support her to have her say at meetings in person or in writing, and share the content of her written reports to encourage her feedback and involvement. This approach gave Imogen an opportunity to develop her insight into concerns for her welfare but also to balance professional views with her own opinion:

> *She comes to meetings... and I would always take a wee bit of time with her beforehand and… that sort of settles her into it and she is able to speak really well and she'll also put things down on paper for you… Recently I have done the referral... I thought she's going to go ballistic at me with some of the things I've written but… a lot of things she sort of went 'Actually that is fair enough' and equally there was things where she was like 'Absolutely not, I am not vulnerable' but… I would say to her 'Well I have to say that I think you are but I'm going to write Imogen does not agree with this. She thinks…' so she was happy that it was balanced* (Imogen's social worker).

Some 16+ social workers described using a range of person-centred strategies to encourage participation from young people in pathway planning reviews:

> *We will try and keep our meetings and reports short… in the young person's terminology and language… cos I am writing it for a young person to be able to read and understand not for another professional. The other thing that we will do is engage them well before the review… ask them who they want at it... so at the young person's LAC… we will cut it right down to three or four people and then have our professional discussion before that as opposed to making the young person sit for an hour or two hours in a meeting with it going right over their head… That approach has worked really well… That flexibility and being young person centred and engaging them at their level... It's very important that we keep our young people there... and listen to the young person as much as possible* (Jake's social worker).

Some young people depended on family members, staff or carers to support them to participate in decisions and in pathway planning process. For example, Rick's carer explained how she supported him to communicate his views to social workers on matters relating to his pathway plan:

> *I would put forward what Rick tells me. Rick would be quite articulate to tell me what he wants but he would be quite anxious in social settings with other people... so I'll give him support to say what he really wants to do himself* (Rick's carer).

Joel felt unable to make decisions independently mainly due to the effects of his mental ill health and drew upon sibling support in this regard:

> *I have to ask me sisters. I can't make decisions anymore, I don't know if I am right or wrong.*

Social workers also described involving parents and carers in planning processes and decisions about young people's post-care lives, particularly when they supported care leavers to communicate their views and advocated on their behalf:

> *We do an 'About You' assessment form to gather up all the information about his needs... but it's about sixty pages long... In Paul's case I filled that in with his mum... Parents are the best advocates for their kids really, you know, they know their young person the best... and then what I got to know about Paul from observing him and spending a bit of time with him and then asking the staff that work with him as well about his needs* (Paul's social worker).

Declan's social worker also depended on his parents and professionals to advocate on his behalf:

> *His verbal communication is so limited... It's a real challenge for staff to ascertain his views so, therefore, we all have to take on an advocating role for Declan... It doesn't mean we're going to get it right... but you're seeing them every month, liaising with the professionals... and the parents* (Declan's social worker).

Carers also felt that they were effectively involved in pathway planning processes. Chloe's foster carer felt fully involved in her pathway plans and, as a result, felt able to advise Chloe about decisions that might be in her best interest:

> *I am very much involved… in any reviews about Chloe, I would be invited to them and they meet up with me and ask me how she is… and any concerns… They would feel I would know Chloe very well and Chloe has respect for me that she mightn't have for them… If there's an issue I can usually talk to Chloe and get her to see it from a different point of view and then let her make up her own mind after that* (Chloe's foster carer).

Another foster mother also felt she guided this young person towards what she felt were decisions reflecting her best interests:

> *I would give [Anna] my opinion on things for what is best for her… If it's something I'm not 100% about I'll tell her why I don't agree with it… At times she mightn't listen to you at the beginning but eventually she will* (Anna's foster carer).

Lorna's kinship carer compared the 16+ pathway plan with the LAC review process and felt that difficult or contentious issues were addressed to better effect at pathway planning reviews which provided a supported environment with social workers present:

> *The pathway is totally different than the LACs... It gives the kids their place. They want them to be involved in it… They would say in front of Lorna… 'What's going on? What's difficult?' And*

> *Lorna's having to sit there and listen to that which was easier [than] when it was just me saying 'You can't continue to do this'… It's definitely a way, way better system* (Lorna's kinship carer).

However, social workers also highlighted the importance of providing independent advocacy for care leavers with mental health and/or intellectual disabilities:

> *Good representation for the young person and advocacy for that young person, you know, a real driving force for them is important... cos you can compare somebody who has really skilled and able parents who can really strongly advocate to somebody who has maybe their parents have learning needs themselves and support needs* (Paul's social worker).

Indeed, some care leavers felt that former carers dominated decisions about their future and left little opportunity for young people to have an active role in the planning process. For example, Simon wished to make decisions on all matters affecting his life and felt a degree of continued infantalisation as other people continued to make decisions for him as he transitioned from care:

> *I do [have a path plan]... But people are putting ideas inside. Like X [former carer] is busy… putting ideas of her own down... and I hated that. I hate people making decisions for me* (Simon).

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 in 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). Declan's residential key worker gave an example of the level of decisions he was supported to make:

> *Declan is involved in lots of decisions daily from he gets up in the morning… Getting showered, breakfast, activities that he does. If he's given options that he doesn't like he can change them and he'll know to do that. He'll tell you what he wants. He's quite good at making decisions… If he's not happy with something or changes his mind about something he can tell you that as well* (Declan's key worker).

Social workers highlighted the challenge of pathway planning with young people who had overly ambitious future goals and highlighted the importance of a sensitive approach, carefully breaking down higher level future goals into more realistic and manageable tasks:

> *You can have 'I'm going to be a doctor' from somebody with a learning disability... You have to recognise that they are never going to... So you say, 'Let's see what we need to do for you to get there... the first few steps'... Laura had a pathway and she still hasn't lost sight of her goal but we are still at the bottom level, to get the basic education qualifications* (Laura's social worker).

Social workers also highlighted the need to balance consideration of risk or vulnerability and service availability:

> *I have a number of young people who are really doing things that we would consider may place them at risk but we have to respect their age as well... It's trying to get the balance between rights and keeping them safe... Our view of risk is frequently at odds with the young person's view of risk and all you can do is, if you can, get them to agree to basic safety requirements... It is really based on the relationship that you have with the young person... That does stand for a lot because the young people will come to you... when things are not good* (Sara's social worker).

> *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, that level of support is something that they are going to need and living in the community on their own without any supports isn't actually an option. So you could ask them what their wishes are but you mightn't be able to do that* (Belinda's social worker).

In considering rights and risks, the capacity of the young person to understand choices and the consequences of their decisions or behaviours was an important issue:

> *It was difficult with Sam because it was difficult to get a sense of what he was either understanding or he was willing to take on board... It was important to keep the language as simple as possible and explain that on very much his level as best I could* (Sam's social worker).

> *It's that vicious circle if they don't get what they want they can become aggressive or angry you go back to square one again... sometimes dangerous behaviour they get up to and they expect there to be no consequences... There is a real struggle with consequential thinking with the mental health guys* (Johnny's social worker).

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:

> *A lot of times it's whether or not they accept and understand their diagnosis of mental health difficulties or learning difficulties, accept there's obstacles there for them. We've a young person who doesn't accept that he's on the ASD spectrum... That's very difficult to work with because placements are breaking down... There's what they think they need and what we maybe feel would be better for them* (Jamie's social worker).

Social workers emphasised that, for any care leaver, pathway planning was difficult in the context of limited resources and post-care service options:

> *Pathway planning can be more difficult because you don't have the appropriate placement, services or resources* (Jake's social worker).

For example, Danny withdrew from his college course and decided to undertake an employability course but was not able to secure a place due to over subscription. Similarly, Belinda could not participate in choices about her new placement as these were limited to the availability of placements and funding:

> *For Belinda it wasn't a case of saying 'Here are three different supported living houses which one would you like to go and live in?' It was very much directed by the adult team - 'This is the one we can get a place in and that we are able to fund'* (Belinda's social worker).

In addition to the challenge of involving young people, some social workers also spoke of the challenge of engaging other professionals in the pathway planning process:

> *It's having the right people at the meeting to get a good overall picture as to where the young person is. If other people aren't able to attend or haven't been given consent by the young person to attend, it can be difficult* (Tony's social worker).

> *There are certainly other professionals that don't understand what a pathway planning process is... so it's trying to engage them in it and include them in the decision making... It's probably an education thing for everybody involved about what their roles and responsibilities are... When*

> *they then reach 18... you are having to take a step back and depend on others more to meet needs* (Sam's social worker).

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, children's disability social workers and/or transition workers also developed a transition plan for leaving school and moving on from child to adult disability services. These transition plans usually began when disabled young people were in their mid-teens. For example, Simon had a person-centred transition plan co-ordinated by the transition coordinator in children's disability services which involved his care, school staff and social workers from both the LAC team and children’s disability team. However, with the involvement of multiple teams, social workers in 16+ and disability services could be undertaking dual processes of pathway planning and transition planning. One social worker explained how these processes should be joined up:

> *For young people with disabilities the pathway plan process is co-ordinated over two teams... with transition plans... and pathway plans... I have had experience where disability say they have their own process and transition plan and don’t want to know about pathway plans... So our PA’s going 'OK well we’re taking that transition plan and calling it the pathway plan'* (Charlie's social worker).

A strict adherence to each team’s own procedures for planning mitigated against collaborative working across disability and 16+ services. In contrast, 16+ social workers who had been able to work alongside staff in disability services enjoyed more opportunities to develop more person-centred and creative ways of planning for the transition from care into adult life:

> *Because of her difficulties with reading and writing we would have done the PATH to care picture diagram and it would have been the disability social worker and the transition worker that came over to do that with her cos we wouldn't have been familiar with that. So it was good that we worked together to do that for her and the most recent one we did it ourselves with her... We used pictures... and we went over what we done before… and it just makes a lot more sense to Alana. She can see the pictures then she is able to look back and see what you have achieved with college and home* (Alana's social worker).

However, involvement across 16+ services, schools and transition workers could also lead to inaction and delay in transition planning. For example, Linda did not have a transition plan in place six months prior to leaving school.

Social workers who had undertaken person-centred transition plans with young people with intellectual disabilities were very positive about the benefits of this approach as Simon’s transition coordinator described:

> *It’s just a visual way of trying to plot for Simon where he sees his future and then trying to break it down into steps as to what needs to happen and when. We could share that with the people that are involved with him so that everybody knew what he wanted and how we could best help him work towards that… We held it in school... and it’s done very, very informally but Simon did really buy into it... It did focus him on doing the work which he now felt was meaningful, like the cooking, budgeting and timetables... It sounds a very simple piece of work, but it certainly worked for him at the time... really settled his anxiety levels way down and at least he could see that everybody was listening to him and... we’re acknowledging this is what he wanted to do... and this is what we’re going to do about it... and he was very well supported with the psychologist who knew him really well. He had him well prepared before he came in, 'We’ve talked about this, is it ok for me to say that this is a worry for me?'* (Simon's social worker).

However, other social workers in 16+ teams were concerned about the time required to undertake such person-centred planning:

> *With the guys with the learning disability... I went to the person centred planning meeting... for two hours and he had all his friends in. He had his mum, his granny, former foster carers, everyone he wanted there. We had a wee party for him and when I came from that meeting I can see exactly what this lad wants to do with his future. Exactly who he wants to live with... But this was all one day about him. Could I sit and do that with any of these fellas who have the mental health issues? Not in a million years* (Danny's social worker).

Plans set out formally could give young people a sense of security as they knew what the future could hold for them and what support may be in place as they moved into adult life. For example, Imogen found it helpful to explore supported accommodation options with her social worker as part of her pathway plan. However, in many cases, intentions documented in pathway plans often changed or did not transpire for the young people. Alana described how her plans for employment in a local shop did not materialise due to a shortage of jobs. She was successful, nonetheless, in securing a position working in a day centre, following voluntary experience in the same setting. Alana's change of circumstances, however, did not prompt a pathway review and, by the time of the final interview, at 21 she still had not participated in a review of her pathway plan in almost three years.

While the pathway plan was generally viewed as a tool to help young people think about moving on from care, even when pathway plans were regularly reviewed, it was regarded as somewhat redundant in terms of foreseeing the future and unexpected changes:

> *It is quite a ridiculous thing 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).
>
> *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).

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

> *Pathway planning... the idea of like having a five year plan is a bit laughable cos who at 16 could say where they are going to be in five years? I couldn't have... We don't need that static assessment. We do care planning and pathway planning everyday with our young person all the times we see them... We go through their health, education, identity, self-esteem, placement* (Jake's social worker).
>
> *The best plans or the best strategies in the world can fall apart. It just depends where the young people are at and what they're able to do and manage... Plans can fall apart and things can collapse and it's just a matter of going back again to the drawing board and starting all over again* (Chloe's social worker).

3.3.2 Preparation for Leaving Care

The main focus of preparing young people for leaving care was developing their independent living skills, including management of finances, planning meals and making health care appointments. For example, Laura, who had high level mental health needs, was being encouraged to live as self-sufficiently as possible in a supported living setting in preparation for independent living:

> *I do my own cooking and my own washing... Just everything you would do normally in your own flat but there is staff here... 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 what you had to buy and how much electric you had to put on. But I kind of got used to it really, really quick because it is just like a kind of normal thing in here... I didn't just learn off the staff, I learned off the other young people as well.*

Foster carers also encouraged young people to be more self-sufficient, as Jamie explained:

> *She [foster carer] helped me… If I was hungry… she would make me make it myself and help me… Simple things like making your beds, sorting out the washing... She helped me with that.*

Chloe detailed her foster carer's role in helping her prepare for the practical challenges of adult life:

> *I don't think you realise the things you take for granted when you are in a foster home... My clothes were ironed and put in my wardrobe for me. I didn't even have to put them into the washing machine. But when I had said to X [foster mother] I was thinking of leaving… She stopped doing things for me and was trying to get me to do things for myself before I left.*

Similarly, at the beginning of the study Simon lacked confidence regarding travelling independently. However, by the final interview he had undertaken specialist training supported by an occupational therapist at his school and was travelling on public transport alone which enabled him to attend social activities independently.

There were also examples of young people leaving residential care being prepared to undertake more daily living tasks, although preparation for independent living was more limited in this setting due to group dynamics and the home's routines and procedures. David, who spent most of his time in care living in a children's residential home, explained the lack of motivation he felt to undertake more independent living tasks:

> *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... A lot of normal moving out stuff like cooking and washing clothes they do try and educate you on but for me the environment was completely wrong… For example, 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.*

There was particular concern that young people in residential care became institutionalised and were not motivated to learn independent living skills, as Joanne's social worker explained:

> *Young people in residential care are not being appropriately prepared, in any shape or form, to be able to function independently... They become institutionalised. They are used to everything being sort of done for them, as opposed to allowing the young person to do it for themselves. It's almost like a synthetic bubble, it's not true to life... I've had young people come back to visit us once they've left… and they will tell you quite clearly, that too much was done for them... They were not prepared to be able to manage out in the big wide world* (Joanne's social worker).

Similarly, social workers noted young people in foster care homes could lack opportunities to develop independent living skills and engage in peer activities as foster carers were wary of allowing young people in their care to take risks:

> *Independence skills... are lacking within a lot of foster homes. There is the fear from foster carers to take those risks* (Laura's social worker).

Despite several examples of how young people were being prepared by professionals and carers for independent living, there were cases where care leavers felt ill-prepared for adult life and voiced their dissatisfaction with the preparatory support offered by professionals:

> *They just throw you in at the deep end. Just go do it yourself* (Jake).

> *The preparation was crap, absolutely crap. They didn't tell you how to manage your money or nothing* (Joel).

Indeed, some social workers were shocked at the daily living skills young people lacked and their limited life experiences:

> *One of the youngsters I taught to shower everyday... You are thinking 'Oh my goodness, kids of 17 years of age and they don't know how to wash' and he said 'You know that was the first time anybody taught me how to wash'... Then you realise I need to go right back to your very basics* (Laura's social worker).

> *Just very basic practical skills like 'Can you make a meal?' 'No'. 'Can you use a microwave?' 'No'... Can't use the washing machine… What is going on?* (Laura's social worker).

Young people who were inadequately prepared often felt that their leaving care experience was a hasty process as they went too quickly from being dependent on carers or staff to having to rely on their own self-sufficiency. These young people felt that whilst they were in care they had all of their practical and emotional needs met and became over-dependent on carers which detracted from opportunities for them to develop their independent living skills. For example, Tony stated:

> *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... 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.*

Likewise, Jake, a young person with Asperger's syndrome, discussed how he struggled with everyday responsibilities of making appointments because such tasks were always completed for him when he was in care:

> *You would be afraid of... ringing up folk or booking appointments... and get registered with dentists… Just stuff you're not used to doing... that people would have done for you anyway then when you have to do it your like 'what the f**k do I say?'*

In addition, young people were unsure how to deal with challenges that arose such as, addressing tenancy problems or arranging for household equipment to be fixed. For example, Tony's foster carer noted how he struggled to deal with housing organisations in a professional manner:

> *He still needs help… in terms of getting stuff done*. *He's had to ring the housing executive to sort things out in his flat... He might begin to struggle where he doesn't get the answer he wants or expects… dealing with conflict situations… keeping them cool and rational* (Tony's foster carer).

It was also noted that some young people with complex needs struggled to engage with proframmes aimed at supporting them to develop the skills required for their post care lives. For example, Tony admitted that his lack of readiness this was partly due to his own disinterest in engaging in preparatory activities:

> *Mentally I was like a bag full of cats... I wasn't prepared at all... I didn't have a house to go to, I didn't set anything up like that. I didn't have any job prospects and I didn't really know where I wanted to go in life and I still kind of don't. The way I left care was… I wasn't prepared at all due to my lack of interest in being prepared.*

Likewise, Connie, who had a history of absconding from multiple placements, explained how she was not skilled in coping with everyday tasks because she had not engaged in preparatory skills training:

> *How am I meant to cope on my own? Like not having staff to do things for you, like weird boiling a kettle on your own.*
>
> Interviewer: But had you been prepared for things like that… independent living skills?
> *Yeah... but I never done it. I was always out, I didn't care.*

Even when young people did access support to learn independent living skills and support from carers, they often still struggled to put their learning into practice when they left care. For example, Chloe's former carer felt frustrated about her lack in interest in learning to manage her own affairs:

> *She would be quite happy to let everybody do it for her... making doctors' appointments, everything... There was a lot of budgeting work done with Chloe… but she still struggles with budgeting* (Chloe's former carer).

Most young people emphasised the importance of having an opportunity to actually experience having responsibility for a range of independent living tasks whilst still in care. Such stepped approaches to leaving care would give care leavers an opportunity to practise doing things for themselves with support provided, if needed. Preparatory courses also need to be tailored to the varying needs of young people leaving care. Some felt that these courses were often focused on care leavers engaged in substance misuse and criminal behaviour and did not wish to associate with this negative peer influence, as Chloe explained:

> *There was an independent living programme 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 had four lines this morning' and I was like, 'that's not going to help you live on your own'… I just left. I wasn't there to talk about drugs or how much you could drink in the weekend… They were looking for me to do cookery programmes. I wouldn't do it because I knew the type of people that were going to be at it and they just crack me up. They complain that they have nothing and have no qualifications and then they do nothing to get any.*

Similarly, Laura's social worker explained how she refused to participate in a relevant employability programme because she did not want to be associated with the other young people attending who she perceived to mostly have a history of criminal behaviour.

3.3.3 Being Ready to Leave

Efforts were made by professionals and carers to render the leaving care process as smooth a transition as possible for young people, minimising stress and anxiety. Identifying and preparing a new place for care leavers to live was a main focus. For those planning to move in with birth parents, a phased return home was planned. For Alana, who wished to return to live with her mother, a phased process was put in place to ensure she did not leave until she was ready:

> *I used to have one night a week, then it went up to a few nights a week so I could get used to staying with my mum… After I turned 18, I waited a couple of months… I very happy that I was moving back to my mum's, even one night a week because then I knew where I was going.*

Other young people were not so prepared for life after care and were fearful of moving on:

> *I wasn't really prepared no... I felt a wee bit scared, unhappy and not comfortable... They told me [about] a roommate… I didn't really know what a roommate was so I was a wee bit scared but... as soon as I came here I thought give it a try and it worked.*

Anxiety provoked by apprehension or uncertainty about leaving care could be particularly acute for care leavers with ASD, as David explained:

> *I started worrying about moving out two years before I actually moved out. I worry about things way ahead… I do a lot of worrying to myself.*

Young people often felt that they had left care before they were ready to move on. These young people sometimes exited care early on their own volition due to dissatisfaction with 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 made the decision to leave care and end contact with social services as soon as they turned 18. However, social workers and carers were concerned about the welfare of young people who left at 18 without being adequately prepared for adult life. These young people often later regretted leaving care so quickly as there was no way back into former placements. Once they experienced independent living for the first time, they often realised they were not as self-sufficient as they had expected:

> *I was quite stubborn and wanted to be independent quite quickly and I found out the hard way that I couldn't be… I wasn't prepped for it and 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).

Similarly, Chloe decided to move out of her long term foster placement despite having the option to stay with her carer, citing altruistic reasons. She later regretted her decision but was unable to return to her former home as her carer had fostered another young person:

> *I left so someone else could have what I had… Because there was people a lot worse than me. I am quite happy. I had a job and Tech and a car when somebody out there had nothing... If I could do it again I maybe wouldn't be in such a rush. I could still be at home [GEM placement] now but I'm not… someone else is in my place.*

Her carer described Chloe's desire to move and subsequent disappointment:

> *She thought having her own space would be brilliant and just couldn't wait to live on her own… She very soon realised that it wasn't all that she thought it would be… It was cold and it was damp. There was a lot of noise from the street… She was very lonely, isolated… She was finding the budgeting very hard… and then that impacted on her mood* (Chloe's carer).

Young people leaving residential care were expected to leave care when they reached their 18th birthday. Although there were plans for phased approaches to moving on to post-care placements, young people leaving residential care felt they had limited choice and often left residential care abruptly. For example, although David was happy to leave his children's home to move to independent accommodation, he felt his exit from care was rushed and he did not feel that he fully participated in leaving care decisions.

> *My whole leaving care time was very rushed in a sense anyway… We had a meeting and everybody was making these decisions about me and not even bothering to ask me what I wanted. So I just told them 'Right I'm going, none of this staggering out'. I just got sick of being told what to do.*

David's PA explained how he had left residential care at a much earlier stage than envisaged in his pathway plan:

> *A month before he was due to be out... at a meeting he just decided now's my day to go. One of the failings at the time I suppose was the phased support with regards the contact the residential staff were to have with him for the 6 weeks afterwards... The demands then on residential staff with new children who came in and he got a new key worker the week before he moved out so a lot of things were thrown on their head* (David's PA).

At the start of the study, Imogen was very discontent living in a children's residential home and planned to move out when she was only 16 years old, although she explained how she also felt scared:

> *In most ways I do feel ready to move on but in some ways I'm like very scared. I just want out of here... I want to be able to have control over my own life and not have people telling me what I can't do... I want to do it myself so I do want to leave but in a way I'll probably miss some of the support I have... But I don't think I'll miss this house or the staff* (Imogen).

By the time of the next interview, Imogen, at 16, had left the residential home of her own accord once approval had been formalised as she felt her placement was untenable. She did not wait for a follow on placement to be secured and lived temporarily with birth family until her supported living placement was confirmed. Soon after leaving care, Imogen's mental health deteriorated resulting in hospitalisation. However, in her final interview, she still felt that leaving the residential home was a good decision, although she had left abruptly without support in place:

> *When I left I already got the ok from the panel, I just had to wait for a placement... leaving [the children's home] I was out on a limb but I think it was kind of better just to go and not think about it, because thinking about it would have made it difficult. So it was just better to go.*

3.3.4 Ongoing Support from Foster Carers

At the time of interviews six young people were still living with foster carers with one young person still in care and five living in GEM placements. In these cases, carers continued to play an active role in the lives of young people in their care and were considered as long-term family relationships. Tina's social worker explained the benefits of the extra support offered to those in GEM foster care arrangements:

> *The GEM scheme gives you a bit of time to prepare for independent living… That's better for someone with a learning disability to have that additional time cos they don't hit 18 and maybe act, feel or have the same knowledge as another 18 year old. I think the GEM scheme in general is brilliant to have that extra bit of time to stay in care if someone wants to* (Tina's social worker).

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 support. Even when care leavers experienced a reduction in contact with their former foster carers, they still played an important role in their lives. For example, Simon who had recently moved to supported living, had reduced contact with his former foster carer but still described her as someone who knew him very well:

> *X [former foster carer] still knows the insides out of me... She's not that close now cos I don't see her enough... She'll come and see me now and again.*

Continued support from former foster carers when young people had left care was greatly appreciated by care leavers. Although Sam had left care and was living in a supported accommodation, his former foster carer was still in regular contact throughout the duration of the study, as Sam explained:

> *We're getting along very well… We speak on the phone quite a lot and we're organising to go out together. So that will be good.*

As discussed above, Chloe's carer remained a valuable source of emotional and practical support. At the time of the interviews, Chloe was in touch with her former foster carer 'most days':

> *I would invite her round for dinner or I just call and see her. We could go out for lunch or for a coffee. She could come home here and have a shower, a bath... There's a spare room there and she can go to bed here and just feel pampered for a while* (Chloe's former carer).

Despite not living with her carer anymore, Chloe also commented on how regularly she availed of her informal support and how she considered herself part of the family:

> *She is my foster carer and I go home twice a week for dinner… I can call in anytime I want… If they were going shopping at the weekend they would always ask me to go… I am not left out. I am going home for Christmas.*

Despite having access to adult mental health services, Chloe preferred to draw on her foster mother for emotional support, indicating she was her main source of support with regard to her mental health.

In some cases, the continued relationship with foster carers could facilitate ongoing informal support and a potential return to live with former foster carers. For example, Jamie moved out of care at 18 to rental accommodation due to a strained relationship with his foster father, however, he continued to enjoy a particularly close bond with his foster mother and later returned to live with her:

> *I'm closer to my foster mum... I can go to her about problems and all that… If I was stuck for money and all, she has put money into my bank… She's helped me with the current benefits I'm on now… filling in paperwork and stuff. I can't hack that... I would come down and help her out… round the house… help her clean up... remind her about her tablets* (Jamie).

The bonds developed with some carers extended well beyond formal roles specified within social service boundaries and, for some, led to lifelong relationships and key sources of ongoing support. For example, Danny explained the ongoing role of his foster carer:

> *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.*

3.3.5 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. Secondly, those moving from specialist children's disability or mental health settings when children reached 18 years old required specialist adult residential care and decisions about such placements were often delayed or uncertain.

Some care leavers who had lived in residential children's homes felt they were disadvantaged by having to leave care at 18 years old whereas others could delay their move from foster care or avail of the GEM scheme:

> *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).

Social workers emphasised that, for those in residential children's homes, the abrupt move from care on their 18th birthday was very difficult and these young people were rarely ready to leave care and move into supported or independent living:

> *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... Practically, I don't think that our young people are set up to be able to manage... Most of them have been 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).

> *Within this last six months we have had three young people with mental health issues who have been involved with CAMHS or DAMHS... and on the day of their 18th birthday go to the housing executive as part of their care plan which I have to say, as a service provider... is wholly unacceptable and doesn't fit with our duty to care to these very vulnerable young people* (Connie's social worker).

> *I think 18+ is one of the most challenging times for any young person... Some young people in residential have to move on the day of their 18th birthday... That's it, they're out...That's scary for a start because the best we can hope for is one of our supported joint commissioning placements* (Dawn's social worker).

Several social workers also noted that moving on at 18 is an unnatural transition too early in the life course and reflected on the contrasting experience of young people in the general population who continue to live with birth parents and avail of their support well into their adult lives:

> *With our own children we wouldn't be saying to them at 18, 'See you later, you are an adult now get on with it'. In particular… if we had a child that had a mental health disorder or a learning disability so I think it needs to be extended... beyond the age of 18* (Joanne's social worker).

> *Some young people don't last too long in their accommodation… There's only so much you can be prepared for the reality of living on your own, getting yourself up in the morning, making yourself meals, paying for your gas or electricity. 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 of adult placements transitions were often rapid and stress-inducing. For example, Belinda's mother explained how they were only informed about her confirmed adult placement in the same week as her move there:

> *The whole thing was a disaster… We were only told where she was going on the week she moved… I didn't even get to see the place. I wasn't given any choice whatsoever on where she was going… I think she did two tea visits, an overnight then moved… Awful… There is no contingency planning. No foresight. It's not organised. Everything is just firefighting at the last minute… It takes a catastrophe before someone will get off their backsides… Belinda's placement should have been sorted out in a week* (Belinda's mother).

Her social worker reflected on the challenge of delays in securing adult placements due to the need for all key stakeholders to meet and agree on the financial arrangements:

> *Adult services had been unable to identify somewhere. There had been several places looked at and they had all either fallen through or there wasn't availability... Whenever the placement was agreed as suitable for Belinda and there would be a place available… The housing executive had to agree that she was a high priority for that place so they will provide housing benefit towards that placement… She eventually moved but with so little time... much quicker than anybody would have liked it to happen... She did find that very hard* (Belinda's social worker).

Accelerated transitions from child to adult placements were often stress provoking experiences for disabled young people. Paul's transition was also rushed in the end, despite several timely planning meetings with professionals and assurances that a suitable placement would be provided. Such uncertainty caused much distress and anxiety, as his mother explained:

> *We felt that the Trust were giving us very positive signals but we were dismayed in the end that we weren't able to say anything to him really until three months before he was moving... Those who are working with him expressed frustration at that cos he was asking… but you couldn't say... It's an awful pity if you have to medicate people to get them through a crisis move… And the house wasn't ready until the day before he moved in. It wasn't decorated cos they couldn't start till they knew they were getting the funding* (Paul's mother).

Similarly, Sam's former foster carer felt that although discussions and planning for his transition started in a timely manner, the actual move to his adult supported living placement was rushed, causing undue distress to the young person. This carer cited bureaucratic protocol of professionals for the delay:

> *It was a bit rushed at the end… There was lots of planning... Everything on paper, lots of meetings. 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 so, although the planning and the discussions happened early, it did drag* on (Sam's foster carer).

Lack of choice in adult accommodation placements and delay as funding decisions were pending also impacted on the emotional wellbeing of some young people:

> *I had a young person left highly anxious by the ambiguity about the future which impacts on their mental health. You were seeing deterioration in her mental health, her self-harm, her withdrawal from others... she said 'well where am I gonna go?' You were left just saying 'Well we don't know yet'... That was very difficult because you can't give her answers... and I don't think that was very fair for that to go on as long as it did... and they're not being listened to. It does take time for an*

> *appropriate place to be identified but I think it could be done maybe a bit quicker* (Paul's social worker).

SUMMARY

For most care leavers, participation in decisions increased as they aged out of care and began to make self-determined choices. There were major benefits of experiences of participation including increased confidence, enhanced capacity to become involved in decisions and improved outcomes for care leavers who were fulfilling self-determined post-care goals. However, staff in 16+ teams often need to undertake preparatory work with care leavers, provide support for them to participate and utilise flexible and alternative ways for them to have their views heard.

Persistent barriers to participation included capacity issues, communication challenges, risk concerns, funding delays and organisational change. For several young people, the effects of their mental health or intellectual disability made it more difficult to make independent decisions and family members played important roles in terms of supporting decisions and advocating on their behalf. However, several care leavers were dissatisfied with the ongoing influence of family members, former carers and professionals over decisions affecting their lives. In addition, social workers emphasised the importance of access to independent advocacy for these young people.

Young people recalled their experiences of pathway planning processes and, while some participants found these helpful, others found it to be redundant, patronising or stressful. More joined up planning processes across 16+ and children's disability services would help to streamline dual transition planning processes for disabled care leavers and ensure accessible, person centred approaches to planning. Preparation for leaving care focused on all aspects of the young people's lives, particularly independent living skills, housing and educational, training or employment. However, young people need more opportunity to practise the skills they learnt and continued support as they struggled to cope with independent living. Indeed, care leavers urged other young people leaving care to make use of supports while they are available and not leave care hastily.

Those who had ongoing support from former foster carers or birth parents valued these informal sources of support. There was much concern for those who exited residential children's homes at 18 who had been institutionalised and may not have had opportunity to develop their independent living skills or informal supports in the community. Most care leavers with more severe levels of impairment who moved from child to adult placements underwent rapid, stress-inducing transitions due to issues of bureaucracy, protocol and uncertainty about the availability of adult services.

3.4 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 after care experiences of managing personal relationships, vulnerabilities, parenting, identities and social networks will also be explored. The section also considers the support offered to care leavers from various agencies such housing agencies, colleges or universities, voluntary sector providers and 16+ services.

3.4.1 Accommodation Options and Support

Types of accommodation and housing available for care leavers varied and included staying with carers under the GEM (Going the Extra Mile) scheme, returning to the birth family home or moving to residential care facilities, supported accommodation or independent housing. The importance of stable housing was emphasised by all respondents, as succinctly explained by Jake's social worker:

> *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).

3.4.1.1 Residential Care

On leaving care, three young people moved from specialist children's residential care to specialist adult residential care settings at, or close to, their 18th birthdays due to the cessation of children's services. These young people had more severe and complex impairments and were not expected to live independently. Efforts were made to create a smooth transition to help these young people cope with the challenge of a change of environment and routine in their new placements:

> *Staff who have a very good relationship with her were doing a lot of work preparing her for turning 18 and supporting her with the changes that were ahead and reassuring her that they would be very much part of her transition... She was finding it all very hard so it was just giving her an opportunity to talk about how she was feeling and ask questions about anything that she was worried about* (Belinda's social worker).

> *We had a planning meeting and it was agreed by everyone there that it wasn't in his best interest for the transition to be discussed with him yet even though it is only about three weeks till he transitions... So social story work will be carried out and that will mean there'll be pictures of the place and staff... a picture of him in his new bedroom... and the door with his face on it so he'll make that association... Staff who work with him... and his family are in full agreement that this is the best for him. Staff from his new placement have been going up to his current placement and shadowing staff working with him so they can see how they could replicate things* (Declan's social worker).

Despite a stress-inducing transition (discussed earlier), by the end of the study, Paul was settling into his placement in a specialist therapeutic community setting for adults with intellectual disabilities and had been able to reduce his use of medication and engage in daily meaningful activities. However, there was concern that Paul may not be able to stay in this residential setting in the long-term, as his social worker explained:

> *There is a cap at age 25. It would be really detrimental to Paul if that wasn't an option for him, if he was expected to come to an adult residential home... You would see a break down in his behaviour and mental health... His anxiety could potentially be through the roof and it could damage relationships with his family as well if they weren't able to manage him... It will come down to funding... It is a bit of a worry and I'm sure it must be wild for his parents to think about that too cos he really does need that supportive package around him* (Paul's social worker).

His key worker also described how the absence of a confirmed plan for his future living arrangement was a source of distress and anxiety for him:

> *We don't know what's going to happen at 25 at all… It causes him quite a lot of anxiety… We had his review last month and there were no plans at all* (Paul's key worker).

Paul's mother was particularly concerned regarding the impact of uncertainty about his future on his mental health and the general distress for the family. Paul's transition into his current adult setting was an eleventh hour arrangement and she feared his post-25 transition would follow a similar pattern:

> *After he's 25 really where else is there for him? And they have no answers. In terms of his transition… they wouldn't put any plans in till two months before his 18th birthday having known about it and talking about it for three years. And we were having to push and push… It doesn't happen till it's a crisis and his behaviour has gone off the rails… That will put them up the line to get a decision made… Like your family has to be on the verge of disintegration before they'll do it* (Paul's mother).

Paul's social worker valued the high level of care provided in his current setting, however, she also noted a shortage in placement options for this group of young people both within child and adult programmes of care, which often meant being placed some distance from home or having no choice of placement.

During the course of the study Declan turned 18 and moved to his adult placement in a residential home for young adults with intellectual disabilities. His key worker discusses his daily routine:

> *Declan is here 24 hours a day... He'll follow a schedule and he will do different activities like water plants… arts and crafts, listening to music… Go out for walks and bus runs... His biggest issue will be helping him to manage his aggression and keep his behaviour controlled. Whenever he runs into difficulties he becomes very self-abusive and can cause damage to property and he can hit out at staff. He needs a lot of support to help him control that and to keep himself safe and others around him safe* (Declan's key worker).

By the end of the study, Declan was continuing to settle into his new environment. His level of medication was being gradually reduced and his challenging behaviours decreased as he benefitted from consistency of staff and familiarity of routine. Declan was also being introduced to a sports club in a local day centre and staff were hoping that he would soon be ready to begin day care in this facility for adults with intellectual disabilities. Although staff were still concerned about his self-harm behaviours and potential future detention in a mental health hospital if his behaviour deteriorated.

A third young person, Louise, who had a severe depressive disorder, moved from an adolescent mental health facility to an adult psychiatric hospital. Upon discharge, she moved to a supported accommodation setting where she was the youngest resident but was reassured that staff were on hand for support at all times:

> *Living here has its ups and downs. As regards the support in it, it is good. Most of the staff would be quite supportive… There is a buzzer system here… If you wake up during the night and you weren't feeling good… or struggling… you can call someone so that part of it is good.*

Louise received a lot of support from her social worker and various other professionals in her first few weeks in this setting, but indicated that this support withdrew too quickly and 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... Maybe having a longer time of intensive support [would help]... I am by far the youngest person here so that can be a wee bit of a struggle 'cos... all the people would*

> *be over 60's, mostly older people... A lot of older men and I stay well away from them... I just spend a lot of time in your room when I'm here* (Louise).

Social workers emphasised that the range of specialist, age appropriate accommodation 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 from specialist care settings:

> *Unless you are on the books of adult mental health or adult learning disability you can't access that accommodation even if you have mental health issues or learning difficulties... You could be sitting in our team with moderate learning disabilities, Asperger's with complex needs but you're still not able to access specialist supported accommodation* (Jake's social worker).

> *A lot of the mental health facilities tend to be geared towards older people and our young people are not interested to going to live in those types of facilities at all... There needs to be more catered towards their sort of age and their needs definitely* (Susan's social worker).

3.4.1.2 Supported Accommodation

Six young people were living in supported accommodation at the end of the study, however, others 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 eventually move to independent living.

Two young people who had been diagnosed with severe intellectual disabilities and ASD/ADHD and who displayed challenging, violent behaviours transitioned to a supported living setting where they shared accommodation with a very small number of other disabled young people and accessed high levels of 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. The supported living settings they moved to were provided by voluntary sector organisations where they could access support staff 24 hours per day.

Sam expressed contentment living in his adult placement which he referred as his 'real house', to capture the permanence of his current home in comparison to his life in care moving around several care placements. Belinda also settled well into the adult facility she moved to, enjoying more freedom to manage tasks independently. Her mother commented on how she was enjoying more a loosening of some restrictions she had previously in her children's placement:

> *When she was in a children's home… they had locked doors. It was just horrible. Now she's got a bit of a life and she's got choices and she can go into the kitchen* (Belinda's mother).

Since moving to the adult setting, Belinda's relationship with staff developed quickly although she missed support workers from her previous placement and living with her birth family:

> *I get along with the staff easier in here and we don't have as many arguments as we did [in children's residential placement]… but I don't like living away from my family.*

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

> *I just have to tell them what time I'm gonna come back at but I don't mind that just cos they need to know who's coming in and out all the time... Sometimes they like to know where I'm going... [I'd like] to just go through one person not 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* (Simon).

Additionally, Simon struggled in terms of isolation as he attempted to get used to living alone after his foster placement:

> *I just like felt strange cos… I missed the company.*

Susan's social worker also commented on the frustrations of young people who were subject to surveillance and rules in supported accommodation:

> *They have turned 18. They see themselves as young adults but there is a restriction on the number of nights they can spend out of the unit and who they can bring in even though it's their own flat... That's a safety issue for them and people living in the same building as them but for the young person I'm sure it just feels like they are constantly being told how to live their life and that's probably very hard* (Susan's social worker).

Other young people moved to supported living placements for care leavers which were not disability services. Young people in these settings were able to access varying degrees of support, as required. Imogen, for example, received more intensive support in one of these supported living placements, as her social worker explained:

> *She would have her own wee flat but its staffed 24/7. There would be still key worker set up and they're very experienced staff team... They're great because they involve the young people, you know, they would all cook a meal together, go to a theatre show... to develop those relationships and get her familiar with the staff team* (Imogen's social worker).

Access to key workers or link workers in these supported living placements was an important source of support for care leavers as they gradually prepared for more independent living. Many social workers highlighted the valuable role of these specialist supported placements for care leavers with additional needs:

> *I have to say how important the staff and her experience there was... We had sort of wrapped care around her... and just constantly kept in contact... Connie would acknowledge that herself now too... They were vital* (Connie's social worker).

For those requiring less intensive support, young people emphasised their new sense of independence in these settings. Alongside this independence, young people also highlighted the importance of being able to access support when needed. For example, Tony moved from his foster placement to supported accommodation where he was assisted by staff to develop skills for maintaining tenancy and managing finances:

> *I was actually very lucky to get into supported housing... Absolutely fantastic… They helped with budgeting and just general maintenance and keeping your room clean.*

In addition to encouragement and support from staff to develop practical skills for adult life, care leavers also had access to valuable emotional support in these settings. Dawn described her experience of a semi-supported living arrangement where she enjoyed the freedom she had longed for, while simultaneously availing of reassurance from staff members as and when required:

> *I was quite eager to get out of care… I was just like 'Happy Days, I have got my own space. Freedom'… They actually had overnight staff there… on call so anytime that you needed them… They would have come up and give you a hand… or a wee chat and a cup of tea.*

Similarly, Laura, who had severe mental health needs, liked her supported living placement and had developed close bonds with her support workers:

> *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... and during the day there is two.*

In most cases, young people viewed supported living as a temporary residence or a stepping stone to securing an independent home. For example, Simon viewed his recent move to a supported placement as a temporary measure until he achieved full independence:

> *I like this place… for the time being 'cos I need it… but I want to move somewhere out in the open... 'cos it's supported living. I don't want to be depending on people all the time… and actually I want to be on my own.*

Two of the main challenges for social workers in relation to supported living was the limited provision of such placements and the reductions in spending which hindered the development of tailored support for young people moving into supported accommodation:

> *In the past, I suppose, we've been able to create more specific placements... We were able to... rent a property and staff would've put in support and you could be a bit more creative about the locality, type of housing, whereas now budgets are extremely tight and it's less flexible. I guess you're trying to maybe fit into the resources that we have... There's no way of knowing when a place is going to become available. You might end up having two or three places in a short period of time... and you may not have one then for a year or so... Service delivery and funding between children's and adults' is not always the same... It's still not as seamless as it should be* (Simon's social worker).

This uncertainty about access to supported living placements meant that young people needed to be prepared to move when a placement became available, which may be earlier than expected. For example, Simon was living in a GEM placement with a view to learning the skills he would need to manage a supported living placement, however, he was advised to apply for a supported living placement to ensure he was on the waiting list when one became available:

> *We have the application in and he'll be considered when placements come up and we'll just review his situation and whether that's something he wants to consider at the time… It would be very much based on the assessment of his needs… We would hate to think that he didn't get an opportunity… or lost the place* (Simon's social worker).

In the end, Simon and his carer decided to take up the first placement that became available in his preferred supported living setting close to his former foster home. This move was sooner than originally expected but it was a decision that he did not regret, as his social worker explained:

> *He sees this very much as a positive move for him, as he sees himself as having the same opportunity as other young people without a disability. He wants to be able to move on and be able to work and live independently* (Simon's social worker).

There was also a lack of supported accommodation for those with acute mental health needs, as Sara's social worker explained:

> *What she needed was accommodation... where she would have mental health professionals on site who understood... and maybe didn't always have that panic reaction to things. A lot of the accommodation with that support on-site were for much older people.... and she had absolutely no hope of getting a flat because the residents had been there so long... We are not going to place a young person in an accommodation with people who are generations older than them because that's counterproductive to meeting their needs so there seems to be something failing our young people... Our accommodation for care leavers will not take responsibility for medication... 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).

Social workers recalled various cases of young people with mental health or intellectual disabilities for whom they had struggled to secure appropriate supported accommodation:

> *We would have a number of care leavers with learning disability and mental health who... just do not have the skills or the ability for independent living and securing specialist accommodation for them is very, very difficult. What we have is appropriate... there's just not enough of it* (Lorna's social worker).

There were also challenges in terms of the admission requirements for more specialist supported living settings. For example, one provider of accommodation for adults with mental health needs required tenants to be compliant with taking their medication for six months prior to admission.

Social workers and PAs also commented on the lack of supported accommodation options across the region with many settings based in urban areas which would displace those from more rural areas:

> *The lack of supported accommodation here is a problem... If you were to compare with the high 24 hour seven day a week support in accommodation that sits in Derry or Belfast, there is no comparison... but that means young people moving away from some of the other supports that have been in their local area so there is a big debate about displacement... They are very vulnerable to suggestion or falling into the wrong destructive company* (Fran's PA).
>
> *We have actually a young person going into Women's Aid despite the fact they didn't fit their criteria… That was the only available place for them... There would be a one semi-supported living place but again it has a high waiting list... It all boils again down to availability* (Joanne's social worker).

3.4.1.3 Independent Accommodation

Twelve young people were living in independent rental accommodation during the study, either from private landlords or the housing executive. However, 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 who moved to rental accommodation also complained about the inadequate conditions of their home including essential appliances that needed repair and environmental issues. For example, Chloe revealed during her first interview how she struggled financially to manage her flat and tolerated poor living conditions:

> *I need more money… and a house that works… The fire doesn't work. The heating doesn't work... The field mice... are in and out of everybody's flats. I had pest control out two times and they just keep coming back… and the neighbours are nuts.*

Chloe remained in this accommodation for almost two years due to its proximity to her college before moving to a more suitable apartment. In addition to poor living conditions and being stretched financially, Chloe and some other care leavers felt isolated due to living alone for the first time. Chloe visited her former non-relative foster carer's home several times during the week for meals, emotional support and companionship:

> *I go home (former foster care home) but when I am not home 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.*

Securing a tenancy with a friend was one solution to isolation. Both Lorna and Tina were living in rented accommodation with close friends. Tina's housemate was another young person she had met while being treated in hospital. Lorna's housemate was also a close friend and she discussed how they supported each other with budgeting money and paying bills:

> *The week she gets paid she buys whatever we need and the week I get paid I buy the food, gas and electricity and stuff. We just take it turnabout… It works out better. It means then there's always a bit of money left over at the end of each week.*

Care leavers who were parents had also struggled to secure suitable tenancies for their family. Sara, a care leaver who was also a single mother of a young baby at the time of her first interview, had moved twice in the previous six months due to attempts to secure a suitable living arrangement for herself and her child. Sara's first home was unsuitable due to inadequate heating:

> *It was a bad house. The heating didn't work or and it wasn't good for me and the wee-in. So I only lived there six months* (Sara).

Jack also found it difficult to find a suitable living environment for him and his son. He moved around various houses that were either unsuitable or temporary, before settling in a privately rented home. However, his PA noted the impact on repeated house moves for Jack on his attendance at college, eventually leading to his withdrawal from his college course.

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 for interacting with peers, agencies or professionals involved in their lives. For example, David, who had Asperger's syndrome, was living in a private tenancy but struggled to communicate with his landlord with regard to the upkeep of his home:

> *I wouldn't have the best confidence going to my landlord and necessarily asking to get some maintenance done in the house. I don't want to be annoying. That's my type of mind-set.*

David's PA explained that he had struggled to maintain his first rental property on leaving care and, when he moved on to a new home, his PA accessed a support worker from a local voluntary organisation to help him to manage this tenancy:

> *It's about learning... not to fight with his landlords but put demands on his landlord and use us to put demands on his landlord as we pay his top up for his rent... David wasn't taking care of his*

> *house... so the support worker took on maintaining a decent standard of accommodation in the next house and... he has maintained it to a better standard* (David's PA).

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:

> *One young lad who would have the severe mental health issues and ADHD... I took him into the housing executive... and within five minutes he walked out... We can only try to assist the young person in getting to those places and ensuring they have... anything they're entitled to... but there's very little more we can do* (Danny's social worker).

Tony, who had mental health needs, struggled to manage all the day-to-day responsibilities of independent living since his tenancy in a supported housing project ended:

> *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, your 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.*

3.4.1.4 Staying with Carers

At the beginning of the study, six young people were living with carers in GEM (Going the Extra Mile) scheme placements. 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. These young people staying with former carers had varying levels of intellectual disabilities or co-existing disability and mental health needs.

Two care leavers, Anna and Rick, were fully integrated into their non-relative foster families and planned to stay there beyond the course of the GEM Scheme, as a permanent living arrangement. Anna addressed her foster mother as 'mum' and also enjoyed feeling fully assimilated into the extended foster family.

Similarly, Rick had been with the same non-relative foster carer since he was six years old and his carer had extended their home to provide him with longer-term independent accommodation. Social workers reflected on the development of such long-term fostering placements, emphasising the significance of consistent long-term relationships with foster carers for young people:

> *Anna is part of this family truly 100%... Anna potentially could have had a massive amount of moves through the system and her carer really hung in there and toughed it out through a really difficult period with her and saw through what that was… Just that consistency and somebody just sticking in there… to see it through to now that lovely relationship that they all have where she's part of the family... People wouldn't even know that Anna was in care you know, just assume, she's her daughter... I have no concerns whatsoever that she won't have continued support because that's her family… That will always be her home and she'll always be there as long as she wants to be... if the GEM scheme didn't exist, she would be there still. It's not about money for the carer* (Anna's social worker).

Some young people living in GEM placements found it helpful when there was a focus on developing their skills for independent living, which also required a change of house rules as young people reached 18:

> *Simon had it in his head, 'Once I'm 18 I can really do my own thing and you'll not have boundaries around me'... His carer was telling him 'You don't have to leave me when your 18. If you want to stay with me and learn to do all these things, that's fine I can teach you'. Then Simon agreed... There are rules within the house about what he can do at 18 that he couldn't do at 17 and he's been doing a lot of preparation work for that and I think that has helped a bit* (Simon's social worker).

The challenge for young people was 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:

> *There is an issue with how the GEM carers change speed when they turn 18... The carer has to understand that we're now dealing with an adult. The young person has to understand they're still living under somebody else's roof with their rules... Sometimes the carers find it harder than the young people... because they're so used to being foster carers and putting down structures and working in a certain way and they find it hard to change gear* (Charlie's social worker).

Social workers noted that two challenges for the GEM scheme were the requirement for the young person to be engaged in education or training and the reduction in financial support for carers.

> *Not all foster carers pertain to the GEM scheme as there is an awful drop in money but what is proposed is that at 18 you should be in training or employment so you should be starting to contribute to the home anyway or supporting yourself in some way* (Dawn's social worker).

> *He's post-18 and his foster carers had agreed to take him back with the GEM payment but... he's not in education or training so we don't pay the GEM… So his foster carers got nothing* (Danny's social worker).

Simon had originally stayed with his carer under the GEM scheme but later moved on to supported living. For his former specialist carer, the financial impact of continuing with Simon's placement was an important consideration. However, the decision about funding from adult services was uncertain until close to the time Simon was expected to leave care:

> *The carer would've been getting an enhanced allowance and... what normally happens is they would move to GEM up until they're 21 and then it goes under a shared care arrangement within adult services... but one of the difficulties was trying to get decisions between the GEM scheme and the adult team around that funding... The resources aren't readily available within adult services so it takes a bit of time to look at that... That wasn't ideal in that we were coming to 18 and we couldn't tell the carer until very close to the time where Simon was going... We are looking at a more definite pathway as to how that can be replicated within adult services* (Simon's social worker).

However, 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:

> *The GEM scheme and the shared care scheme with adults where families are in a position to continue on with those placements, has been really positive... There isn't this expectation that*

> *they must go on their 18th birthday and there's that really consistent, strong support for those young people, that has continued. We've had young people then move onto shared care within learning disability services, and they're in their 20s and 30s and that's lovely because a lot of our young people will always need a level of support and care* (Simon's social worker).

3.4.1.5 Returning Home to Birth Family

Four care leavers were living with birth parents and/or siblings. All of these young people had been diagnosed as having intellectual disabilities (co-existing with mental health need in one case). Reunification with birth family worked best when there was a phased return home with support and preparation for both young people and birth parents, as Danny's former carer explained:

> *They tried him at home first of all for a few nights, then the weekend, then the week. There was a nice transition for him to go home… We negotiated... How are you going to share the bills? What are you going to do if things go wrong? Who does the cooking? Who does the cleaning?' All that kind of stuff … That work took place over a period of six or seven months prior to his moving home* (Danny's former carer).

For others, returning home was a short lived experience. For example, Sara returned home for a short period before moving on to independent accommodation. Social workers also commented on 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. Conversely, in other cases, young people with mental health or disability related needs were welcomed home but their parents were not able to meet their needs:

> *I've someone who has learning difficulties and mum will be more than happy to take him back but we know if he goes back it will be disastrous for him cos mum won't be able to provide the level of care he needs but if he chooses to do that at 18 all we can do is be there to advise and support* (Tina's social worker).
>
> *99.9% of the time the lads who have the mental health issues aren't gonna return to families successfully... If they do go back it's gonna end up breaking down and relationships are just fragile… and the impact then that that has on the young person cos it's rejection yet again... 'Oh my Mum doesn't want me. She can't handle me'* (Danny's social worker).

In some cases, care leavers were looking forward to returning home but were unexpectedly let down by their birth parents, as in Jack's case:

> *The plan was for him to go back and live with his mum and his siblings... We developed that relationship over time and then about six weeks before that was due to happen mum met a new partner and they moved and said 'No we don't want him'* (Jack's social worker).

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 without the level of support that would have been formerly provided by children's social services:

> *Some just gravitate back home because it's home and it's mum and dad... That's difficult then because if parents haven't had any good support themselves then everybody's right back into that situation that didn't work in the first place* (Imogen's social worker).

> *The most common place for someone to go when they're 18 is back to their families, often their abusive families... We do see a kind of a cyclic, almost reliving of events that led to them coming into care. So disputes with mum or dad that led to them coming into care… and then getting kicked out and then back... So you see that kind of thing go around and around... unresolved family disputes, especially with people with mental health difficulties and parents who have mental health difficulties as well... exacerbated by alcohol and drug use* (Charlie's social worker).

Many social workers expressed reservations about reunification with birth parents where there was a history or neglect, abuse or negative influence on the young person. Some social workers expressed concerns about the vulnerability of care leavers to manipulation or abuse on return home:

> *I had one person who had always been very keen to return home and the worry was that that young person would actually be exploited in some way by their parents to care for a younger child or even financially exploited... and we would be concerned about sexual or physical abuse by one of mum's partners and neglect issues* (Norah's social worker).

Simon's social worker and carer had been worried that he would return to live with his mother on leaving care due to concerns about the negative impact this would have on his emotional wellbeing and his vulnerability to exploitation. By the end of the study, however, Simon had moved to a supported living placement and felt a sense of guilt about not returning to her care. His social worker helped him to explain to his mother that he wanted to live independently using a visual person-centred transition plan:

> *He didn't see his future back with his mum... That was one of our concerns that he would maybe feel obligated to go back to his mum and that might not necessarily be the best arrangement for him... But then he was clear, that 'Yes I want my mum to be part of my life but I don't want to move back there'. So we met with his mum and we put the PATH plan up… because mum would've some learning difficulties as well, so the visual thing worked quite well and Simon was showing her on it, 'Look mum, this is my future. I have drawn you in it. I am still going to go and see you but this is my house and I want to have a house of my own'.*

Care leavers returning home could also present risks to younger siblings which could lead to their exclusion from the birth family home, as Connie's social worker explained:

> *Parents aren't able to have the young adults back because they have to protect their other younger siblings particularly if there has been aggression or violence within the home or maybe poly substance misuse or self-harm issues and the impact of witnessing that on younger siblings would definitely lead to child protection issues* (Connie's social worker).

Some social workers noted that returning to birth family could encourage care leavers to disengage with 16+ services. Linda had very limited contact with 16+ staff and her mother encouraged her to cease involvement with social services. Similarly, Louise's social worker discussed this familial influence which could limit access to support services:

> *Young people would be influenced by their parents so if the family have a history of non-engagement with services then it's more likely to make the young person not engage with mental health services even if they need it* (Louise's social worker).

Alana's case demonstrated the different approach social services had for care leavers who, as adults, could make their own decisions about where to live and whether or not to respond to concerns from social services. Alana's social worker explained how risks associated with her return to live with birth family were assessed differently now that she was an adult:

> *Concerns about the standard of the home have always been something but... as a young adult she wasn't going to be put at risk into a home that wasn't as hygienic... We take guidance from Alana as a young adult about whether she wanted those issues addressed and she didn't... Then we feel that we can't go and address them* (Alana's social worker).

3.4.1.6 Moving Around

Some young people experienced repeated moves across temporary or crisis driven accommodation included hostels or bed and breakfast lodgings, with increased risk of homelessness, social isolation and loneliness. 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 which led to lack of upkeep of the property or damage to the home. For example, Jake, who had Asperger's syndrome, was evicted from his first tenancy within two months of moving in:

> *I moved to my first flat… Apparently you get three warnings then you're out… The landlord put three on me… and said 'Right you've got 28 days to get out'… I think everybody wanted me out. I took a skin full of drink one night and near kicked some boy's door in* (Jake).

By the final interview, Jake had moved to another property and was settling in this quieter and inclusive area. Jake's social worker also commented on how he was managing better in his second home and had learnt from his experience of failing to keep his first tenancy:

> *The first rental flat lasted a week because he moved in and he just let everyone in through it. The police were out every day. There were people in it he didn't even know, just a lot of drinkers the landlord kicked him out... He moved into a second property he has been in it now over a year and... there hasn't been one complaint about anti-social behaviour so I suppose with the Asperger's with Jake he really had to try it, fail and then he understands*(Jake's social worker).

Several social workers commented on how care leavers were vulnerable to negative peer influence or exploitation, often due to a desire to avoid social isolation or loneliness:

> *They're letting X, Y and Z into their home, maybe their home even being used for... partying, under age activity, drug use, illegal activity and... they'll not be able to keep people out. That's a huge problem, especially for 16+ young people who...want the company. Because they're so isolated, they let whoever into their home... to fit in with what other people see as the norm... and that has an impact on their tenancy with the housing executive* (Norah's social worker).
>
> *Learning disabled young people who have a smaller peer network maybe have to make themselves available to feel that they do have friends. That can lead to further exploitation... We did have a young person with mental health problems who lost their tenancy because others took advantage of them, exploited them and used it as a party house, caused criminal damage, caused damage to others... He ended up in the juvenile justice centre... just that frustration of how they have been taken advantage of* (Connie's social worker).

Engagement in substance misuse with other young people in care also presented concerns that could lead to criminalisation:

> *Young people who have just left care are vulnerable in that they are trying to maintain the networks that they had when they were in care... and then they have young people from the care unit down in their flat and that causes a lot of issues... Not only does it put that person's tenancy*

> *at risk… It, at times, has ended up where young people have actually been criminalised and there has been police involvement* (Joanne's social worker).

Multiple housing moves, often as a result of anti-social behaviour and negative peer influence, led to a risk of temporary housing or homelessness which restricted young people’s access to essential health services:

> *Quite a lot of those with a mental health condition are transient… They can’t keep the people from the door. They can’t keep the drugs form the door... Then they get into a spiral of complaints... and paramilitaries as well and then they get moved on... I have a young man... who has lost all his points cos he has affectively made himself homeless through bringing in other people... Actually he's living on settees belonging to family and that only lasts so long... And they lose their benefits then so just everything falls in they can’t register with a GP... or access supports for mental health... He has moved so many times we haven’t been able to catch up with him* (Laura's social worker).

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:

> *I had a young person who clearly had mental health problems was actively trying to take his own life but ended up caught up in the criminality side of things as well... The solicitor was pushing for a bail address because otherwise he would have had to stay in custody and to be fair he wasn’t really suitable for being kept in custody either... He ended up in a B&B, got anti-depressants and took an overdose... We all knew that potentially that could have been a disaster* (Louise's social worker).
>
> *On occasion it can be a hostel… putting people who do have moderate learning disability or mental health issues into shared facilities, shared rooms on occasion. So just by reason of a number i.e. you are 18 years and a day you are now going into shared facilities in hostel provision... I think it is shocking. Totally unacceptable... It would be a very hopeless position for them to be in and if they are feeling that this is how a system that cared for me up until I am 18 is now treating me, I would feel very let down* (Connie's social worker).

Young people who moved around or engaged in substance misuse or criminal behaviour were often those deemed to be at risk of homelessness, particularly if they had a limited or negative social network:

> *There is a higher level of homeless from a care related background and... a lot of people within the hostel environment do come across with dual diagnosis say mental health and substance misuse background… and their inherent vulnerability leads them to being taken advantage of, to getting involved in the cycle of substance misuse and subsequent homelessness that can be associated with that* (Connie's social worker).

There were particular concerns for care leavers with mental health needs including a lack of support for those being discharged from hospital or presenting with challenging behaviours:

> *The link between homeless accommodation and mental health is well established and it would be nice that there may be choices for homeless people with mental health problems that have a specific therapeutic element to… stop the merry-go-round, stop the in, out, in, out... but you are involved with adult mental health services and then you’re discharged* (Charlie's social worker).

> *With one of my lads... his mental health had deteriorated... He couldn't maintain the tenancy... The place was a mess... He was reacting to hearing voices by smashing the TV, smashing walls, ripped all the doors off. There's damage to the property now... He's in hospital... but we need to identify supported accommodation for him... He's just gonna mount up a massive rent arrears* (Danny's social worker).

> *I've another young person who has significant mental health needs and... we were trying to get her housed... and because she was coming with so many other issues with lifestyle choices... as well as her mental health problems, that they didn't want to know. She didn't get accepted* (Norah's social worker).

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:

> *I took a lad to housing to register and housing refused to do it because they said he was too high a risk... They simply refused to put him on their waiting lists... The housing sector do risk assessments now on all of their tenants... and there is new legislation to protect landlords so we are running against a lot of brick walls for these young people* (Jack's PA).

> *For someone aged 16, 17, 18 especially if they have any sort of PSNI involvement or any history of sexual offences in any shape or form, it's almost impossible to get them accommodation.. If they've sexual convictions you're not even gonna get them into hostels... So you're looking at unregulated placements then... they're not ideal locations... and compound issues that they already have... We need more accommodation for young people aged 16 to 21 specifically for those with mental health issues and substance misuse... and if there's any convictions I need somewhere to put these guys that's safe for them and that we can work with them in... It's just so difficult because they could end up homeless* (Danny's social worker).

> *Your absolute nightmare scenario is where you have a young person with an arson conviction. You cannot find them accommodation anywhere and of course we're obliged to tell them... They can't go into any supported accommodation units, any generic homeless hostels… and they're sofa surfing and all because they set fire to a bin in a children's home when they were 14... We have two or three young people who basically can't live anywhere* (Charlie's social worker).

3.4.1.7 Support from Housing Services

The main provider of public sector rental accommodation for care leavers was the Northern Ireland 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:

> *We would be involved in writing support letters for the housing executive for move on tenancies but that will involve wraparound supports through floating support and things like that. So there is almost an expectation that these young people because of their care experience will have to have additionality in terms of support post leaving care. To a certain extent almost re-identifies them as ex-care young people* (Connie's social worker).

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:

> *A social needs assessment is part of the housing executive pointing system... If you can highlight that they have mental health or learning disabilities it does tend to give them the opportunity to be placed quicker and the additional pointing* (Connie's social worker).

However, social workers were concerned about restricted accommodation options for those aged 16-18:

> *Housing is getting worse... For the 16 to 18 year olds it is a massive loophole* (Louise's social worker).
>
> *The 16+ workers would often have built up relationships with housing executive staff so that does work very well... but... there are accommodation shortages... There is a real lack of one bedroom apartment for young people* (Sara's social worker).

Social workers also reported gaps in the provision of accommodation, waiting lists for access to accommodation and the quality of housing for those aged over 18:

> *It's quite slow allocation in the housing executive... For one young person it has taken over a year before he was allocated housing... That raises concern because... that will escalate self-harm and overdosing* (Laura's social worker).
>
> *There are limited accommodation options for post 18s… You're left basically with housing executive... You'd be waiting a while. You may have to move into hostels in the interim period. Not ideal either... depending on how they're influenced... There may be issues obviously with an estate itself to do with drink, drugs, criminality, paramilitary activity, you know, and it's just something that's just completely alien to them and how they deal with kind of conflict be it with neighbours you know, it would be a cause of concern* (Tony's social worker).

Social workers were also concerned about variations in point allocation for housing and difficulties with securing suitable housing in a positive area for care leavers:

> *I sometimes feel that they get second best. They get what's coming up. They don't necessarily get it matched with their need. They can get flat accommodation in housing estates in... a rundown area... It could be degenerated into a drug misuse area where... We know that they house paedophiles... and it's variable from office to office how they point them as well... The other day someone had 110 points and someone had 130 points and they both left care at the same time and went to two different housing offices* (Laura's social worker).

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).

Sara's relationship with her floating support worker was also distant:

> *The tenancy support worker… I don't really get on with her to be honest… Actually I don't really hear from her, only if I really need something I would ring her.*

Many young people's experiences of living in NIHE homes were unfavourable with unsatisfactory housing conditions, poor or delayed house repairs and slow responses to queries. For example, Chloe had numerous issues in her apartment and found that calls to the NIHE regarding repairs yielded a slow response:

> *It takes them weeks. I phoned them about a month ago to say the bin went missing… Nothing.*

Jack, a single parent with Asperger's syndrome, was living in NIHE leased accommodation but was dissatisfied with their slow response to his calls for repairs and maintenance:

> *The stuff that doesn't work that really puts stress on you when you have a child. That was the stuff that had me driven insane. And when it came to the housing executive, see trying to get work done?… I was constantly on the phone with social services trying to get them to help.*

His PA explained how he struggled to negotiate with the NIHE and indicated that advocacy from the 16+ team was required to ensure necessary repairs were made to his home where he cared for a young child:

> *He moved into a housing executive house... It was disastrous cos the work couldn't be done… He had the child there. He had to be pushy... and then he was ringing the housing executive and being abusive to them. Then they would ring me and I would say to them 'Look he has a toddler in the home... The child's getting chest infections'. I was very adamant the child's under five in the home... There wasn't a bath and there wasn't a cooker* (Jack's social worker).

Joel was also unhappy with his rental accommodation and wanted to move to a more comfortable place, however, he felt uneasy about moving out and persevered with his current tenancy despite several inadequacies, both in the building and the NIHE's response to his circumstances:

> *I'd like to move... It's wrecking my head the kitchen and all. The housing executive won't do anything about it… That ceiling is all cracked. I came in one day and that was all lying on the ground... You can't even store stuff in the kitchen cos it starts to get all mould. There must be damp or something.*

In addition, some young people 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 physical attacks from members of the local community. For example, Jamie's NIHE rented home had been attacked several times, including vandalism during his period of hospitalisation following a suicide attempt, leaving him feeling under threat in his local community. Jamie and his carer advised that both the police and NIHE failed to respond to their complaints about these attacks on his home and he was not given priority status to be re-housed:

> *The housing executive was useless… They didn't really class it as a threat. They expect somebody to walk through the door with a knife… but they [attackers] actually didn't... physically come in. They just threw bricks through the window and stuff… I was lying in bed one night and this big rock came through the window and it landed right on the bed… It scared me because I was only there by myself* (Jamie).

Jamie's carer felt he had received an inadequate response from the NIHE:

> *The windows were broke. Every time they repaired the window they broke it again. They were throwing great big boulders and rocks into his bedroom and into his sitting room... We got the police and we went to the housing executive and we were told 'No this doesn't count as intimidation'. So they couldn't move him. That didn't put his points up cos that's not intimidation. How is it not? It was dreadful. It was the worst time… and he would have been terrified... He was having nightmares and couldn't sleep* (Jamie's foster carer).

SUMMARY

This section highlighted the various types of accommodation participants moved on to when they left care and their mixed experiences of living in different settings. 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 young people for their move into these settings. Other young people were keen to leave care settings and move into supported or independent accommodation. Whilst these settings offered opportunities to lead more self-determined lives, some young people had struggled to maintain tenancies, had been vulnerable to negative peer influence and found it difficult to cope with limited skills for managing a home. In addition, some young people were socially isolated and their sense of loneliness could impact on their emotional wellbeing and trigger mental ill health. There were also examples of young people who had learnt from their early unsuccessful experiences and had later settled in new accommodation when they had developed their skills for living independently.

Young people emphasised the importance of having a secure home that was adequately equipped and had a reliable heating system. However, some young people had moved into housing executive homes or independent tenancies where broken equipment was not repaired in a timely manner and communication with housing agencies or landlords was challenging. Social workers expressed concerns about the lack of supported accommodation available for care leavers where they could access support from staff who understood their vulnerabilities or had knowledge of disability and mental health issues. Social workers and PAs often advocated on behalf of care leavers with housing agencies when care leavers were at risk of losing their tenancies or were struggling to negotiate with housing agencies with regard to repairs and house moves. However, there were particular groups of young people who were most difficult to accommodate including those aged 16-18 and those or those with unpredictable behaviour linked to disability/mental health issues and/or substance misuse. Care leavers with a criminal record or who were deemed to present with a risk of arson or sexually harmful behaviour had the most limited accommodation options. These groups of care leavers were at greatest risk of unregulated, temporary accommodation or homelessness.

3.4.2 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 and five young people were in paid employment, mostly on a part-time basis. Nine out of the 31 young people were not engaged in any education, training or employment. This section also explores the barriers to engaging in further education, training or employment and the types of support that enable young people to progress in terms of gaining qualifications and jobs.

Engagement in Education and Training

Of the 16 young people in formal education or training, three were studying degree programmes at universities in NI and England, 11 were attending college or employability courses with five completing GSCEs, 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 in preparation for mainstream training and work opportunities. 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.

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

> *I'm getting on really well… It's right up my street and I enjoy it… haven't missed a day* (Lorna).

Similarly, Anna thrived in her course and work placement, as her social worker explained:

> *You just could see her shine because that was just her interest and it was lovely to see her getting out a wee bit more you know, going to the placement, being confident in that... You could see her confidence grow* (Anna's social worker).

Social workers commended young people who had been successful in education or training programmes in the context of adversity. They also emphasised that smaller educational achievements may not have as much recognition by those monitoring educational outcomes for care leavers but were nonetheless significant for the young person:

> *Sometimes the audits in the Department ask how many young people have five GCSEs or whatever but someone who has had a really traumatic childhood, Asperger's, learning difficulties you know their optimal level might be an NVQ level one. It mightn't look much in a return to the Department but to them its massive and a wonderful outcome* (Jake's social worker).

Others were completing targeted programmes for care leavers led by voluntary organisations. For example, several young people attended the Prince's Trust personal skills development course and Include Youth's Give and Take programme aimed at improving employability and self-esteem in preparation for mainstream training and work placements. However, some social workers expressed concern about the impact of budgetary cuts on the future funding of some employability and personal development courses from the voluntary and community sector which provided valued support for care leavers:

> *It is an excellent programme... for young people that don't have qualifications or the confidence and motivation to go to a course... Again the funding's been pulled. It's down to like 10 young people... They used to take 17/18... We need more of that type of project* (Jamie's social worker).

> W*e have lost the employability scheme... I saw the value in that because they fast tracked some of our youngsters to get their essential skills... Our other programme is maxed out so there can be no more referrals* (Laura's social worker).

> *There is another programme... They are having great problems getting their funding continued and they have been a lifeline for two of my young people.... Each plan is to each young person's individual needs... getting their confidence built up... and some of those young people have said 'I don't know what I am going to do when this isn't here anymore'... They were targeting young people who didn't do so well in mainstream, big formal classes... just not ready, so it is a stepping stone* (Sara's social worker).

Two young people were engaged in supported work placements linked to college with support from voluntary organisations. Sam was working in a placement for adults with intellectual disabilities and enjoyed forming new friendships in this position:

> *It's gone well, you know, working. I know a lot of people. I have a lot of friends* (Sam).

Over the course of the study three young people were studying degree programmes at universities. David appreciated his PA's encouragement to apply for a place at university and overcome his social anxiety associated with interacting with other students:

> *I'm really glad that X [PA] told me to go… I would nearly call it one of the best experiences of my life. University life, especially when I had a whole socialising issue… but we socialise at lunchtimes, coffee times … maybe go out, meet up during the summer... it's not necessarily just class* (David).

Managing the demands of balancing self-care with college or university work, however, was challenging for care leavers with mental health needs. Tina reflected on her experiences in this regard and how she struggled to successfully manage a degree alongside her own health appointments:

> *Uni is stressful… 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… I see my psychiatrist every six weeks.*

Engagement in Employment

Only five young people experienced paid employment. One young person 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 and I am just currently out and about viewing other possible job vacancies* (Tony).

Four young people were working part-time and two of these were working to support their studies at college/university. Diane found her part-time job was more manageable than previous, more stressful jobs which raised her anxieties and impacted negatively on her mental health:

> *I love it. My last job was so different… You always had to be at the top of your game. In [this job] you can relax a bit… I don't complain.*

Two young people who were in university and college were also working in paid part-time positions to supplement their income. Norah had benefitted from forming positive peer networks through her part-time position:

> *[My friend] in work. Me and her became friendly. So I've met friends through her. I've met her friends and you know I get on with them as well.*

Chloe enjoyed her job but could not sustain the work alongside the demands of college study as it was impacting on her mental health:

> *I was working but not anymore… I worked for over a year… It was fine. 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.*

One care leaver had developed online entrepreneurial skills and gained additional income by selling products online. Young people had also volunteered in various roles, often with a desire to help other vulnerable young people.

Although low numbers of care leavers were engaged in employment, many of the young people engaged in education or employment spoke of ambitions for future employment. Several were actively completing educational courses with a view to future careers in health and social care or youth work. Other young people were engaged in courses that would help them to realise ambitions to work in science or sports related fields. A number of those attending general work skills training courses or supported placements were also keen to pursue future employment 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 hoped to return to education, training or employment when their children were school age.

3.4.2.1 Barriers to Education, Training and Employment

Overall, just under a third of the care leavers in the sample (n=9) were not in employment, education or training (NEET). There were a number of factors cited by the young people as impediments to progressing in these areas. Seven young people had ongoing mental health needs, anxieties and disabilities that impacted on their opportunity to engage in education and employment. A further two care leavers who were parents of young children did not feel they could commit to study or work, given their caring roles. Care leavers who had a history of disrupted school education also found it difficult to engage in further education or training, including those who had negative school experiences, particularly bullying. There were also concerns about losing their home or social security benefits if they progressed into education or employment.

Impact of Mental Health and Disability

Mental health or disability related needs impacted on the educational, training and employment outcomes for the young people participating in the case studies. Young people with more severe mental health or disabilities had fewer qualifications and found it difficult to secure and maintain job placements or complete further education courses. Some young people with mental health needs found it difficult to make decisions about their future career pathway and repeatedly changed their course of study. Maintaining young people's interest in various courses and job opportunities was an important aspect of the work of the 16+ team which was difficult if not pitched at the right level for the individual:

> *In terms of the learning disability, it's getting courses pitched at an ability that they are going to be able to cope with but also come out with the sort of outcomes that are going to give them the platform to get on to the training or employment ladder… to self-fulfilling careers. Or they are maybe going into jobs that aren't what they feel are going to challenge them and become very disillusioned very quickly. That negative experience then sort of leads to a current cycle of unemployment* (Connie's social worker).

Social workers also reported that young people with ongoing mental health or support needs found it difficult to stay engaged in employment or training:

> *It would be difficult for a young person with mental health needs to access education... To manage a course of education for a year or two years requires some form of sort of consistency, which unfortunately doesn't come whenever you have a mental health diagnosis... For young people with a learning disability that can cause even more issues, just in terms of... getting the support that they require... and it comes to a point then where it actually can be off putting for a young person and they just say, it would just be easier not to do it* (Joanne's social worker).

> *If you've a young person who has problems with low mood, their motivation's going to be really poor. Their concentration is going to be poor and we have seen where they've had to leave courses because of maybe not submitting work on time... It just all piles up and becomes far too much for them and sometimes they will terminate that course because they just can't keep on top of it* (Norah's social worker).

In addition, some young people with mental health needs could not participate in mainstream, group based learning and opted out of education or training programmes:

> *I'm thinking of one young girl who has a confirmed mental health diagnosis and she has literally just wrote off any choice to go into education or training... despite being offered various supports... She doesn't want to go into groups... She's not comfortable in groups* (Susan's social worker).

Social workers also noted cases where an episode of ill mental health at a key educational stage could impact on young people's long-term education and employment options.

> *I have a young person... When she was doing her final GCSE year it coincided with her having a period of really low mood... and self-harming... her placement broke down... The school were refusing to take her back… A kid who had been predicted to pass all her GCSEs and then all this turmoil happened... She didn't do anywhere near where she should have achieved... She can go back into education.... but she's very much of the opinion 'no'... It's a lot to do with her self-esteem... and so much going on for her and her mental health* (Susan's social worker).

Meeting the demands of course assessment and completion could also add to the stress care leavers are already experiencing which could become overwhelming:

> *There'll always be like positive reports from tutors all the way through... His difficulty is come exam times or handing in coursework... It just becomes too much for him and he just can't deal*

> *with it. It would be stress related* (Tony's social worker).

Even care leavers who achieved qualifications commented on the impact of poor mental health on grades. For example, Chloe passed her college course, however, she felt she did not reach her full potential due to deterioration in her mental health at that time:

> *I finished my first diploma and extended diploma with all distinctions. Then I didn't go to Tech and I was dropping out and… I was raging with my grades... only two distinctions and six merits.*

Despite the impact of Chloe's mental health on her college grades, she progressed to secure a place at university by the end of the study. Her former foster carer recalled difficult periods when Chloe's mental health needs and negative maternal relationship almost led to her disengagement from education and her feelings of pride at Chloe's achievements:

> *She was getting expelled... I was getting phone calls about Chloe being drunk... smoking, having unsupervised contact with her mum... Chloe just wanted to give it all up… leave [school]… I said 'If you're having a bad day, you can come home'… and she did. She changed it and she went to the Tech… I'm so pleased with her. She's done brilliant* (Chloe's foster carer).

Some care leavers with social anxieties or low self-esteem also struggled to form and maintain friendships. For example, Chloe referred to peers she interacted with at college as *'Not really friends. They are just Tech people'*. Indeed, she was worried about having to share accommodation when she moved to university. Similarly, Joel cited fluctuating mental health as the main hindrance to completing a college course and felt his low moods and social anxieties were impacting on his progression:

> *I am doing nothing with myself… I would like to do… even an access course or part-time... but then it's social anxiety... For a time there I was alright but then... my moods are kinda up and down. I would be scared to… I wouldn't want to lash out at anyone.*

By the time of his third interview Joel explained how he had started a new course, however, he expected to be expelled from college due to non-attendance directly related to his mental health:

> *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... I went back there last week but left early then missed this week... I get anxious before I go then when I'm there I am usually alright but sometimes I feel like I just want to run out of the room… and don't come back.*

Social workers and PAs also emphasised that social aspects of training and employment could be difficult for some young people with mental health needs or ASD linked to uncertainty about how to interpret the behaviour and communication of others:

> *He can get himself in a fluster... like just dealing with a bit of conflict he might have with the lecturer or... people on the course starting to snipe at each other* (David's PA).

> *I think when you go in to a classroom situation... the teacher is telling you what's going on and that's not gonna work with Danny... If it's a peer challenging him I think Danny's attitude would be rather than fight just to run... I think that is all part of his of his diagnosis... It's a big barrier... It's the autism that's holding him back from further and higher education* (Danny's social worker).

Maintaining personal care and fitting in with peers were further challenges impacting on engagement in further education, as Laura's social worker explained in relation to another case:

> *I don’t think she could manage a work placement at this stage because of her personal hygiene issues... When she went to the Tech course... she struggled with peer relations because they called her smelly... but any mention of hygiene and she loses the temper... and has been violent in the past* (Laura's social worker).

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 were likely to fail to succeed in the absence of necessary support:

> *Whenever there are learning difficulties there can be a sense of 'Well I’m never going to be able to do that anyway'... They are reluctant to begin something that they already think they are going to fail... One of my young people has been assessed by the IQ board as just below that category... but don’t present as someone with learning disabilities so... they have never been told that there is a reason that they find it difficult to learn... They find it so hard to maintain a place in education so they drop out, think they are stupid, they have failed again... There are so many factors in play whether there is supportive people around you who are going to encourage you to... better yourself or putting structure to their day* (Tina's social worker).

When young people were finding it difficult to engage in education and with peers, support was important. However, educational support was not always available. For example, although David was doing well at university during the time of the study, his PA explained that he had previously failed a HND course, due to inadequate support:

> *He went on to do his first HND which he failed. I still blame the lack of support and the lack of understanding... Now at university he has had a certain amount of support but it hasn’t also been the level of specific support that David needs* (David's PA).

Similarly, Dawn’s former carer commented on her college experience in terms of it being an unsupportive environment for young people with intellectual disabilities:

> *Dawn went for school where she was very closeted and very, very well looked after. Then she went to college and… she was with people with special needs… They were watching DVDs, doing very little work. Nobody cared. It was really appalling… I don’t think her needs were catered for in there at all* (Dawn's foster carer).

Social workers also noted how some young people found it difficult to take direction from employers, particularly those who had an authoritarian approach, that impacted on their ability to maintain stable employment:

> *A lot of our care leavers have issues in terms of maybe not being so good at taking direction from other people so that is not going to help them in terms of getting into employment. Maintaining a job for a lot of our young people is nearly unimaginable. They aren’t used to that kind of stability* (Tina's social worker).
>
> *He would be quite a stubborn person and I think in kitchens where you’re given clear direction, 'do this, do that' if he doesn’t see the reason for doing that, he won’t do it and it’ll lead him to... come into conflict with people... He would have issues with taking direction... It would definitely be to do with the approach they take with him* (Tony's social worker).

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:

> *I don't think she liked the way that she'd been asked to do it so it kind of escalated into a row… I think it was a bit of miscommunication… She basically was refusing to go back. They weren't telling her she couldn't... but once she had that in her head, that was it... She doesn't find it easy to resolve conflicts* (Imogen's social worker).

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:

> *You are doubly disadvantaged because you are a care leaver… Through no fault of your own you haven't had the same stability that has enabled you to get a core element of qualifications... appropriate adults and family members... are often absent too... and that's compounded by mental health issues Asperger's or learning difficulties* (Jake's social worker).

The approach of education and employment providers and their level of understanding and support was critical:

> *We are trying to sort of talk to employers about the needs of care leavers… A young person might have a problem with anger management or might blow up about something or might not turn up one day and it could be because of they've lost their accommodation or their father's been round and had a row with them... So giving them a range of scenarios to sort of get them used to the idea that maybe this person has a few more barriers to cope with than the normal employee. I think those can be useful to create more understanding employers* (Charlie's social worker).

Access to support in employment settings was important for many of the care leavers and was a significant barrier for those with more complex or multiple needs. For example, Belinda's mother highlighted her specialist support needs and, as a result, did not expect her to engage in employment:

> *For Belinda to work, she is going to need someone there who is medically trained who can administer her medication… I mean who's going to do that?… She has to have 24 hour care... the job agency wanted her to come into an interview for work and I nearly laughed... Belinda will never work… She would not listen to instructions… and she hasn't got an awareness of danger... She lacks a lot of common sense* (Belinda's mother).

Social workers working with young people with more severe levels of impairment felt that the opportunities for work placement and employment were more limited but were hopeful of their future participation in supported employment, as Belinda's social worker explained:

> *The options are much more limited... We hope that she will be able to take on a training placement rather than day care… but she will always need one to one support so actually doing what people might call a normal job will not be an option for her but there's no reason why with the right support she can't find something fulfilling work wise to do but it is very limited in what placements there is available there* (Belinda's social worker).

Social workers also commented on how, for care leavers with more severe levels of impairment, there was a focus on securing an adult residential placement rather than engagement in further education or training:

> *Our young people would be in school till they're 19 so... in the transition to accommodation, their education and employment needs... kind of goes by the wayside... The focus is probably on getting their placement secured... It's a supportive thing really too that the young person does remain in school until they are 19 cos at least they're not facing those multiple transitions at 18... At least*

> *they have that supportive continuity of school while their home life is changing* (Paul's social worker).

A few social workers, however, commented that there is a greater range of specialist training and work placement provision for those with intellectual disabilities in comparison to those with mental health needs:

> *I think the ones with disability... tend to have a wider opportunity and specific placement schemes for them but there aren't any specific placement schemes for people with mental health difficulties* (Charlie's social worker).
>
> *In my experience for the guys with the learning disability there are different courses available. There's the support there in terms of taxis... With the mental health there's a constant struggle.... We had the employability service which would have been one to one working but that's not available anymore* (Danny's social worker).

There was also concern for those with borderline impairments who did not meet the criteria for specialist support:

> *I think those with a mild learning disability can get particularly lost because... there probably are more resources for the ones with higher need. The ones with mild and moderate can be really isolated cos they don't really fit into anybody's boxes then. They probably have the abilities to do it but there's things then like maybe travelling to and from that could throw that young person or communicating in social relationships within work. You know all of that they need that wee bit of support and then I don't know how readily available that is if you've a mild or moderate learning disability... You're at a disadvantage nearly cos you are that wee bit more able* (Paul's social worker).

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. For example, one young person's work placement was postponed indefinitely, as she was living in secure care due to ongoing mental ill health and risky behaviour. Similarly, Connie had to leave her placement due to fluctuating mental health needs, as her PA explained:

> *Connie loved the wee placement… She did really well with that. But after a dip in mental and emotional health one time, the doctor said definitely the demands of work were too much for her… because her mental health deteriorates so badly, so rapidly… So her GP has recommended she should not work for at least a year... We need to concentrate on getting her well... Too many demands and we would be setting her up for a fall* (Connie's PA).

Removal of expectations to engage in training or employment was welcomed by Connie and her PA who felt it was unfair to apply norms for education and employment to young people who had experienced high levels of trauma and continued to 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 risk concerns. For example, Sam was required, as part of risk management plans, to be supervised during his contact with members of the public which hindered his work placement opportunities. Social workers also commented on cases where risk averse decisions taken by education providers restricted opportunities for care leavers with more severe levels of impairment:

> *I know one young person who really isn't coping well in school at all... absconds... but she goes to college one day a week and she absolutely loves that... but school have stopped that because of the risk of absconding while at school... I know you have to keep that young person safe but... the one thing that she could engage in is actually just all being stopped because of the risks... She'd probably excel if she was given the chance to but then again that probably comes down to whose gonna fund additional staff to take that risk with her?* (Paul's social worker).

When specialist provision was offered to those with support or supervision needs, there were also issues related to uptake of such services. Social workers acknowledged that a range of courses tailored to the needs of care leavers or disabled young people were available, but noted that some young people refused to access these courses as they wished to disassociate from these labels as care leaver or disabled:

> *There do seem to be... a lot more courses that are tailored towards entry levels for our young people with mental health and or a learning disability. The difficulty is, again going back to the person's self-image of having a disability* (Connie's social worker).

For example, despite support needs linked to numeracy and literacy difficulties, Alana's social worker explained that her desire to minimise disability could prevent access to necessary support for training and employment:

> *I am just anxious her difficulties in reading and writing... That could be her downfall in that she would make out that she is able to read it... and it's difficult if people perceive her as more capable than what she is... because she is so mainstreamed… Everything she is doing is accessed through a generic course so there would be a danger that her disability could be overlooked or underestimated... She has just to ensure that if she does try to go on and do anything academic that she would get the right support to achieve that* (Alana's social worker).

Despite the obstacles linked to care leavers' mental health or disabilities outlined above, it is important to note that a small number of young people had excelled in education and were successfully completing university degrees. In some cases, pursuing alternative ways to complete courses was important. For example, David described being 'terrified of secondary school' and, therefore, transferred to a special school where he successfully completed his GCSEs. Later, when he was not performing well in a college course because of anxieties linked to travelling some distance using public transport, he changed the pace of his study to part-time and moved to another college which reduced the need to use public transport. David, like others who progressed to higher level education, also benefitted from having a support person who encouraged them to reach their full potential.

Disrupted and Negative School Experiences

Issues relating to 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. For example, Laura had experienced many placement moves which severely impacted her education and friendships:

> *I moved schools eight times. I was in five different primary school and three different high schools, so I never really got the chance to like make proper friends or even do school work altogether… I was moving so much… then I started health and social care... but didn't finish and about ten other ones.*

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

> *I would have been in a day and suspended for three days. And I just used to laugh at it... It wouldn't have bothered me in the slightest. There was nothing they could have done.*

School experience of bullying also had a major impact on the lives of care leavers, including their engagement with further education or employment. Danny had experienced a disrupted school life due to bullying and challenging behaviours which eventually led to his exclusion from two schools. Danny did not pursue further education or training when he left care. He rarely left home, fearing verbal and physical abuse, which was a major hindrance to pursuing a job or college course as his social worker explained:

> *He is very much caught in that past trauma through school bullying or other peer groups giving him a hard time. That holds him back... He's just 'No I don't need this'* (Danny's social worker).

Imogen had a long history of experiencing bullying at school, leading her to present with challenging behaviours. However, she was later placed in an alternative educational placement for young people with social, emotional and behavioural difficulties where she had more positive experiences and gained qualifications:

> *All the bullying when I was in high school and primary school... They just decided to pick on me when I was young til my temper burst and it didn't happen no more... There was no little miss nice girl anymore... Then I didn't get bullied no more... Well I got kicked out of school... I went to X (specialist school) then... That was fine. It was good. I got a couple of GCSEs there.*

When Imogen was later diagnosed as having ASD, her mother felt her limited progress at school was linked to a lack of understanding and support for her disability related needs, which were more adequately met at the alternative educational placement:

> *She didn't understand the lessons… Then they literally just sat her out in a corridor on her own. When she went to X [specialist school], they kind of were more in tune with children learning at different speeds... She did get the equivalent to six GCSEs in the end... She had some wee meltdowns in it but they're more trained to deal with that* (Imogen's mother).

Jamie also described the impact bullying had on his education:

> *I got bullied in primary school, at a very young age… At the end of primary school, I was just finally giving up on learning* (Jamie).

Social workers were aware of the impact of bullying at school or college in addition to ongoing challenges for care leavers in relation to forming positive peer relationships:

> *Everything was great in school but she had all the boundaries and the rules and the regulations. And then going to college was a big step for her... It didn't work for her at all... She actually ended up being suspended a few times... getting herself involved with a bit of a crowd and it was lack of engagement and bullying as well* (Dawn's social worker).

Tony's father felt that a combination of struggling with school work and teachers who failed to connect with him lead to his son not doing well in school:

> *He did poorly all the way. It was very difficult to get him to do his homework... He had one teacher who really clicked with him… She was absolutely lovely and she thought Tony was brilliant… and*

> *could get him to work… But she was a supply teacher. She left and then it all just collapsed again* (Tony's father).

Social workers also emphasised the negative effect of poor relationships with peers and teachers and low expectations for care leavers' educational progress:

> *I've had one young person in residential who said that he just couldn't attend school because the teachers, one in particular was none too pleasant to him, says that he would never amount to nothing as somebody being in care and really picked on him... I find society creates this impression that young people with learning disability and mental health problems are non-achievers... That's reinforced a lot I think by schools as well. Tutors and teachers at times can lead a lot of young people to believe that because they are within care that they can't achieve and that becomes a self-fulfilling prophecy for young people… To even be able to go into school every day to learn becomes very, very difficult and then you find it's easier not go... and the likelihood of academic success starts to deteriorate* (Joanne's social worker).

Previous experience of school disruption continued to be a feature of care leavers' experiences of further education. For example, Jake, who had been diagnosed with Asperger's syndrome was looking forward to beginning an access course with ambitions to attend university. However, by the third interview, he was struggling to keep up with the course content and engage with other students with whom he felt he had little in common:

> *All the rest are like in their 20s and 30s... seem to know their plan in life and what they want to do. I'm still kind of a bit lost…. because I moved to a different town, I left school and then there was about a three year gap... There would have been a lot of fighting and stuff in school so I just didn't go to save myself the bother and I wasn't interested in going... 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 and I know that… So I think I would rather just drop out than just fail it at the end anyway… It's kind of a career path that I do want to take on but I know I won't be able to do it because I'll never be able to get the qualifications for it.*

Leaving school early with few or no qualifications had a significant impact on opportunities to progress to higher education courses which often required at least 5 GCSE passes:

> *As far as school goes... I got kicked out of school so I left with a D in Maths which didn't really get me off to a good start in life* (Tony).

> *For a number... their ideal career is it's some sort of nursery nurse, health and social care or childcare... obviously very demanding, very sought after courses. The criteria to get into them then someone with a learning disability isn't ever met because they don't have that academic success or qualification... They're not going to have 5 GCSE passes* (Lorna's social worker).

As a result, many care leavers accessed employability courses that 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:

> *There is a real range of options... in terms of getting their foot in the door and getting them into the way of education and work placement... Our employability team looks at your personal development and... CVs. Then you go to your work placement… building up your experience and getting you a wee bit more employable... As you move up from your essential skills to A level and*

> *university there is less of that support... That is hard for someone who has a relapse and needs that support again* (Tina's social worker).

Social workers based in rural areas also indicated that there were fewer options for care leavers outside urban towns or cities:

> *Employment options here are very limited, even pre the recession it was very difficult for young people to get employment or meaningful training... Again the rural Trust comes into it too because... if you live out in outlying areas a lot of times they are having to travel to get to a course and that's very difficult for them and an added expense* (Jake's social worker).

Disrupted Adult Lives

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

> *Education and employment goes way down the list and other things take priority, like for example the housing and ensuring that their mental health needs are met and are stable* (Joanne's social worker).

Ongoing personal issues also impacted on attendance and participation in courses. For example, Sara experienced domestic violence which affected her attendance and led to a withdrawal from her college studies.

Substance misuse had led to the termination of Diane's employment. Diane reflected on her spiral into unemployment and the lack of support from her doctor and employer:

> *I was actually doing quite well in my job at the time. I got promoted… 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… I had to leave… I had went to the doctor and I explained to him... I was getting to the point where I couldn't even leave the house never mind go into work... The doctor put me on the sick for six months but didn't give me no support whatsoever towards going back to work.*

Tony and Jake were also concerned that enrolling on some courses would adversely affect the financial benefits they were receiving. Social workers reflected on their concerns that young people found it difficult to re-engage with education or employment if they became reliant on social security benefits:

> *A lot of our young people... when they get out of a service, they get on to benefits and they lose that wish to get back into something... even when they have a lot of ability* (Jack's social worker).

Opportunity to gain work experience was another issue raised by care leavers, particularly in the current context of economic recession and high rates of unemployment. Jamie had completed a course but was unable to secure a work placement in that area:

> *I wanted to do joinery but whenever I finished that you had to get a work experience... which is hard. Then I passed it and all then the construction trade just went downhill, so it was a killer. If approached somebody they would have said you have to have a minimum of 8 GCSEs.*

Lack of motivation and willingness to engage was an additional factor for young people. Charlie, who had an intellectual disability, and Jake, who had Asperger's syndrome, both stated that they were not interested in working or going to college. Similarly, Sam who was in a supported work placement for adults with intellectual disabilities was reluctant to return to college to further his qualifications:

> *I probably would be scared going into a new Tech and meeting new people again... I like things the way they are… I would say no to Tech* (Sam).

Strained family relationships, chaotic lives and ongoing difficulties were also contributory factors for disengagement from education, training or employment, as Norah explained:

> *My grades all went downhill because of the problems going on at home. I didn't revise … I was sitting on A's and B's on almost everything… everything was looking good but it all just completely went downhill. From a B in coursework… my final result was a fail.*

Another barrier to care leavers' progression in education, training and employment was transport. Some care leavers did not feel confident or safe travelling alone on public transport. Jamie had worked as a decorator but due to a lack of his own means of transport he was unable to fulfil potential contracts or maintain a steady stream of work:

> *I actually done… wallpapering… for a wee while… I'm not doing that now because I don't have a car I can't really travel too far.*

Not being able to drive or lack of access to a car was also linked to missed job opportunities, according to Tony's father:

> *Transport is a major bar to either getting a lot of jobs or applying for a lot of jobs… Even if he got his driving licence… the insurance would be £2,000 a year… The stuff he's looking at is generally speaking 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).

Parental Responsibilities

Parenting roles also impacted on engagement in further education or employment. 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. For example, Joanne was working part-time but had withdrawn from her college course as she struggled to manage the demands of parenting and study commitments:

> *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).

Jack also explained that ongoing childcare issues had hindered his progress in further education but he planned to return to his course in the near future:

> *I have done level one, two... But I failed the last year in level three… There was a lot going on with the child… He has a Care Order on him so there is a lot to deal with there… but I will do an access course next year… I would rather wait until next year when the house is finished, he's settled in school, no social workers, then go back.*

Jack's PA acknowledged his parenting commitments and also felt that the college had not communicated issues relating to attendance and behaviour in a timely manner:

> *He's done very well... but the college principal... said we need to have a meeting to discuss the previous year's behaviours... but they hadn't made us aware that there were issues... He wasn't keeping up with the work... So he's out this year because of that... It might be best just to have time out... but it's very important he doesn't waste the two years he has done* (Jack's social worker).

Each of the young parents in the study had ambitions for education and employment and hoped to return to their plans in the future when their children reached nursery or school age and their lives were somewhat more settled. Sara revealed long standing ambitions to become a nurse, however, she felt this aspiration was out of her reach, at least for the time being:

> *I have always wanted to be a nurse… but I may dream on... I don't really have any motivation for nothing... I have got my health and social care and I have got my maths and English and my IT... I could do night courses and then go on to uni... I just don't want to leave the wee one. I'm going to have to at some point.*

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:

> *He might need this time when his child is preschool to not be at college but then if he waits until he goes to school he's lost support form 16+ to do that* (Jack's social worker).

3.4.2.2 Support for Education, Training or Employment

There were a range of sources of support for education, training and employment including support from: social workers and PAs in the16+ service; staff in schools, colleges and universities; and voluntary organisations. For example, Norah spoke enthusiastically of the support received from 16+ services in securing financial and practical support for her college course and studies:

> *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 leave 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).

Similarly, Jamie was engaged in an essential skills course with a voluntary organisation and spoke highly of the support he received from staff and their encouragement beyond educational or careers advice. One mentor in particular became a confidant and provided emotional support particularly at the time of his suicide attempt:

> *All I have to say to him is 'Do you mind if we have a wee chat?' and he brings us into a wee room and just talks about things… We have a lot in common so I find that a lot easier… He was there whenever I was in hospital… just giving me advice … to help me and make it easier... He's helped*

> *me a lot... He doesn't really pressurise me... He doesn't text me every day saying 'Are you going to be in?'... I would say what days I want to be in… He's been good.*

Chloe was assisted by a careers advisor in her further education college with information about course eligibility and university application procedures:

> *She tells me what to do. She keeps me right because you need science and she was like there is a way you can get around that by being a mature student because I am from a HND background... and I wouldn't have a clue how to do a personal statement.*

Sixteen plus teams had developed good working relationships with course providers and local colleges that helped to facilitate individualised support for care leavers:

> *We would have quite a good working relationship… for example the regional college came to our last team meeting and they gave us information on the link person for every campus and if we have any issues regarding our care leavers before they start the course they will have a meeting and they will be able to get them additional supports and anything financially they can give them so that has become a lot more proactive* (Jake's social worker).

> *I have a young man in college and I met the course tutor... because of his particular needs and I tell you it's a wrap round service... I get an email from them, 'He's not been in today'... They knew I was ringing this young person at quarter to 7 in the morning to make sure he was getting up out of his pit to get there and that's helps... because this was at the edge of breakdown because of non-attendance... You have to have a good working relationship. You can't expect them to do everything. They can't expect me to do everything* (Laura's social worker).

Care leavers often had individual education plans at college and staff understood their particular needs and offered some flexibility:

> *Colleges like to be made aware and the social worker and the young person go to a meeting with the designated support worker and they sort of do up a plan. For example... they were able to give her extra time in exams... That's a real positive* (Louise's social worker).

Young people attending university courses received financial, practical and emotional support from 16+ teams. However, one social worker reported that funding was more uncertain for college courses or lower levels courses:

> *Further education can sometimes be a little bit vague as to the funding arrangements... It feels that we prop a lot of money into young people in higher education because they're the kind of kids we talk about... Somebody who got their NVQ 2 in hairdressing doesn't sound so impressive but those people probably need the funding just as much... So I'd like to see more of a focus on how we support those people in wider courses* (Charlie's social worker).

In addition, some 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:

> *I did have a young person recently who was known to mental health services who started the essential skills programme but it was that big class setting, a teacher at the front of the room and telling them what they were expected to just go and do... It just wasn't for them. They just can't cope with it. So if we had maybe more one-to-one maybe tutors available or even offer it in small group settings* (Norah's social worker).

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:

> *I just think the Trust in terms of a corporate parent... could be definitely more proactive... They could be ring-fencing employment opportunities within the Trust for our young people... We are actually terrible at it... We are going out and asking all the other agencies... but we are not doing it ourselves* (Connie's social worker).

However, others were confident that employability services in the Trusts, including work placements, were working well:

> *We have an entire employability team in this Trust, who do a lot of very good work. They can organise Trust based work placements which work very well... because there's a PFI target on trying to make sure that the rate is not lower than the general rate for youth unemployment... We tend to be exceeding the target* (Charlie's social worker).

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

> *Under the employability scheme... he got on well with the people in it and felt very supported in it... The second placement was just amazing for him it pushed his boundaries no end... They found him very capable... and he flourished out of it* (David's PA).

Similarly, Anna was progressing well in her work placement:

> *Her placement is really positive. You can really see her confidence… She worries that she's not able to do as good as other people would but there's none of that now… She's totally at home in the placement… totally knows her own skills and abilities and is confident that she's doing a good job* (Anna's PA).

In addition to employability and skills development programmes offered by voluntary organisations aimed at supporting care leavers, study participants also gained support from disability-related voluntary organisations:

> *They liaise with the local colleges... and there's a job skill programme... They would do travel training when the young person is still in school... so they can travel independently to and from college to and from their placement site… They also take over like a supervisory role in terms of obtaining a placement for them and then supporting that placement for them* (Declan's social worker).

Young people attending university were supported by advisors in relation to all areas of their studies and emotional wellbeing. They were provided with additional time, a private space for exams and note-takers, if required. By the time of the final interview, Chloe had begun her degree and described the support she received as a care leaver at university:

> *[The university] is very good. There's a care leaver's bursary… I don't have to pay back… and they paid to have me assessed… I have a widening access officer because I'm… a care leaver. She's very good.*

At university, care leavers could also access a financial bursary and tutoring to support their studies. For example, David secured weekly tutoring assistance for each of his modules and was aware of other sources of monetary assistance available to him:

> *I get a care leavers bursary and then because of my health I also get a special support grant.*

In contrast, one young person who had moved to England had difficulty accessing this support and, by the end of the study, she still had not secured the bursary she was entitled to as a care leaver and continued to struggle financially during her studies. Overall, however, respondents were positive about supports available at university and the 'Tick the Box' initiative which encourages care experienced students to state that they have been in care on their university application form, so that they can be informed of extra support provided by universities.

Whilst most young people who were engaged in education or training were positive about support available to them, several indicated that they had unmet support needs. Simon, who had an intellectual disability and mental health needs, felt that he would not be able to manage on a course without his former foster carer's support:

> *There is [a college] but... I don't know how good the place is and I don't know how supported they are… There was a course I did a year ago… and I asked them could I take my work home instead… and my foster carer could do it with me and show me exactly what it means because the teacher usually just explains it once and that's it. And the teacher didn't mind as long as I got it done … But I don't know if that will happen now.*

In addition, some young people with intellectual disabilities, autism or mental health needs struggled to use public transport to travel to college or university. David described how careful management of his tight budget and extra support from social services to obtain his driving licence meant that he was able to drive to university and continue on his educational pathway:

> *If I hadn't properly managed my money I would not have my car and I would not be able to go to university cos the bus is not a suitable option… The Trust paid for my driving test.*

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, stronger 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:

> *One of the difficulties is the employers have their pick... These days we have graduates who can't get work and that sometimes had a knock on effect for our young people with disabilities... And we very much do rely heavily on services from voluntary organisations who already have those working partnerships with employers* (Sara's social worker).

SUMMARY

This section of the report detailed care leavers' experiences of education, training and employment. Several barriers to their educational or employment pathways were identified by the young people including: disrupted/negative school experiences; chaotic adult lives linked to ongoing family or relationship difficulties and lack of understanding/support for mental health needs and disabilities amongst education providers and employers. Despite these obstacles, three young people were engaged in university degree courses with three others were on pathways to third level education. 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, particularly in relation to dealing with difficult issues impacting on their education and helping to promote their self-confidence.

3.4.3 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. Many 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:

> *They would have given us £70 a month to buy clothes and I would have always bought trainers, but then you don't get it. To me they are setting you up for a fall* (Chloe).

Similarly, social workers reflected on the higher level of finances available to young people whilst in care compared to their aftercare experience of living on a greatly reduced income, particularly for those leaving residential care:

> *As much as staff and the system felt that they were doing a good thing... All this clothing and all of this, that and the other is not... real and when kids go out into the big bad world... it disappears overnight... Then they can't function and they're not going to have £200 or £300 to be able to go and treat themselves to 5 or 6 rig outs or they are not going to be able to afford to get taxis everywhere* (Joanne's social worker).

Some social workers also indicated that the extent of financial support they could provide had reduced and some groups of care leavers had more limited support than others:

> *You ask for setting up home and you are given 500 when they need 1000... I had a youngster and... the Trust doesn't buy him anything because he's in a unregulated placement... If he was in a foster placement he would get £178 but because he lives in the community, not because he chooses to... because there are no foster places for him, he doesn't. He gets the raw end of the deal* (Laura's social worker).

This section of the report addresses care leavers' access to social security benefits and sources of support and assistance with managing their finances. Young people's experiences of financial struggles and debt will also be explored.

Access to Benefits

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 entitled to Disability Living Allowance (DLA), several were in receipt of child care benefits and one young person was receiving Carers' Allowance.

There was concern that care leavers could develop a dependency on social security benefit income. For example, Alana ensured she only worked part-time hours when she gained employment so her benefit income would not be affected. Social workers also commented on how dependency on benefit income led to low levels of motivation to engage in further education or employment:

> *The over dependence on DLA is a huge issue... It's this 'Why should I have the motivation to get into education? I'm very comfortable where I am. I can sit all day'... Financially… he gets more in terms of his benefits than if he was to decide that he was going to get qualified in something and*

> *go out to work. It would be a dramatic drop in the money that he is receiving so he doesn't feel it is worth his while in terms of education* (Danny's social worker)

Similarly, Tony felt restricted by the inflexibility of the benefit system as re-engaging with education would impact on his housing benefit and risk losing his home:

> *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.*

Some of the care leavers aged 16 to 19 who were engaged in education or training were entitled to Education Maintenance Allowance (EMA). Laura explained how she was saving this allowance towards a setting up home fund:

> *We get EMA for being at Tech... so that's quite good. It lets you get some savings going… I save about £20 a week... That will go towards a deposit… to get started.*

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. Jake described the importance of setting up home grants to help furnish accommodation:

> *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 for me to get my bits and bobs of furniture and my bed and that.*

Similarly, Joanne had used this income to furnish her home:

> *Social services give you a setting up home grant… I got £500... to buy wardrobes and chest of drawers and a bed... Then they're helping me with the advance rent.*

Joanne had also secured a community care grant which she was using to fix flooring and her former carers provided additional financial support to purchase soft furnishings for her new home:

> *Social services gave her some money but there's no way it would have even give her the basic needs. So we stepped in financially and the whole house is done up now* (Joanne's carer).

Not all young people were aware of the regulations pertaining to claiming benefits and had built up significant fines or arrears. For example, one parent spoke of how his son unintentionally fell into debt due to claiming a benefit he was no longer entitled to:

> *Tony didn't tell the benefits office that he had stopped going to college even though he was intending to go back... When it was found out the housing executive said he owed rent… and the benefits office also said that he owed them… because he was collecting the wrong benefit… So he's got a huge rent arrear and he's also having to pay back an overpayment of benefits* (Tony's father).

Similarly, Tina's social worker described how lack of awareness of changes to benefits resulted in additional charges and made Tina feel wary of claiming further benefits:

> *A few years ago Tina was meant to change from income support to JSA and hadn't realised she was meant to do that... It was a number of months later that social security realised... and she was going to be charged hundreds of pounds... We've written numerous letters to social security saying... she shouldn't be getting charged for it all but it's never really been resolved... That's*

> *probably why she doesn't want to claim the DLA cos she has a fear of people saying later actually you weren't entitled to that and you need to pay it back* (Tina's social worker).

Young people with more severe levels of impairment who were living in high support residential settings used their benefits to support expensive care packages as Paul's mother explained:

> *All their benefits go there… His placement was something like £2,000 a week because of the number of staff who have to be involved* (Paul's mother).

Belinda's mother was unhappy that her daughter's disability allowance did not match her care needs:

> *The problem is DLA awarded her low rate mobility even though she has drop seizures and refuses to walk… and moderate rate care even though she has 24 hour one to one staffing… So I'm in the middle of trying to appeal that… because she needs a car because she lives out in the country and the bus won't pick her up for school … and also to get her to go out more... She also needs the high rate care to pay for her place there… It just an absolute nightmare* (Belinda's mother).

A few social workers in children's disability services 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:

> *We have used direct payments and we have used self-directed support for some of our young people in transition to do a more creative package for them. Now, none of my care leavers, so far have used that* (Simon's social worker).

Support with Managing Finances

Several participants indicated that having experience of living in and leaving care had equipped them with knowledge of a range of sources of financial support and an ability to navigate the benefit system with ease. For example, Jack, who was a single parent, knew the benefit system well and was confident in dealing with all matters relating to his financial entitlements. He was also able to draw on payments from social services in relation to his care leaver status and to support his parenting role, for example, to pay for heating oil. Others were holding down jobs alongside their studies to fund their education. Some had accessed support from family or 16+ services but were keen to manage independently. For example, although Joanne was financially supported by carers to set up home with her baby, she did not tend to ask them for money:

> *She's doing fantastic... managing her money very well. She knows what she has to go out. She knows what's coming in… She knows we're here but it's very, very rarely Joanne would ask for anything* (Joanne's carer).

However, for most, managing financially was an ongoing challenge requiring support from 16+ teams and family or friends. For example, Jamie reflected on the support he received from 16+ services to manage his finances:

> *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 and other basic stuff you need. So I wasn't just being fired in there and just having to do it all myself. I wouldn't have been the best with money, I used to gamble a lot.*

Most care leavers who were claiming benefits were also assisted by their social workers, PAs or carers to liaise with social security and housing agencies and to process benefit claims. For example, Chloe's former carer described the support she received from the 16+ service when she was moving out to live independently:

> *They helped her with setting up home... They sorted all the benefits with her, spoke to the landlord, paid the deposit... They did a lot with her and they continue to* (Chloe's carer).

Charlie, who had an intellectual disability, was also assisted by his social worker in terms of access to a programme to learn how to budget and manage his finances:

> *It was difficult at the very start because I mostly spent my money... X [social worker] helped me a bit... She had me on some kind of scheme where you go and learn... what way to budget out the money... Spread it out… it's getting better. I am going alright now.*

Care leavers with more complex needs were given additional support to manage their finances. For example, Sam, a young person diagnosed with a severe intellectual disability and ADHD, accessed assistance from staff in the supported accommodation where he lived to allocate money for household bills before spending on other items or social activities.

Family and friends were also sources of support in terms of budgeting and finance management. Tony's friend helped him to set out a budgeting plan:

> *I am very bad with money. I can't hold on to it. It's terrible. But a friend of mine would actually 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'. And he would help me in that respect because he does have a much better understanding of how everything works than I do.*

Tony's parents also supported him by helping him save money, as his father explains:

> *He still lacks discipline on managing money. What he actually does now is if he does get any over, he gives it to his mother to hold… That's his way of putting it beyond his reach so that he can't spend it, which shows a certain level of maturity in itself* (Tony's father).

Social workers expressed some concerns about the role of family members in managing the finances of care leavers, particularly for those deemed to have more limited mental capacity or in cases where family members had previously been involved in the neglect or abuse of the young person:

> *Young people with learning disability in particular are sometimes very financially well off in adulthood and the challenge is exploitation by family... You've been able to protect them up to 18 from family but post-18 it's their choice… what they tell family about their financial situation and sometimes you can see families draining them of their money... All of a sudden family appear again back on the scene who maybe haven't wanted to have contact with them until this but realise hey they're liable to be DLA funded and ESA funded and all of that. And you're trying to say look just be careful but a lot of our kids… just want their mummies and daddies back and don't actually see that they are bleeding me dry* (Lorna's social worker)

Financial Challenges

Many young people admitted to struggling financially, not only due to low incomes but also in terms of budgeting unsuccessfully and accruing debt, as Jake explained:

> *I’m on the dole and struggle a lot with money. I’m skint… and getting into debt.*

Sara, a young single mother, also described how she struggled to make ends meet and relied on additional financial support from social services:

> *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 for the end of the month. I can’t save… Once you get your shopping... his 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.*

Social workers emphasised that when care leavers with mental health or intellectual disabilities were not coping well, they tended to disengage and were less likely to maintain their finances:

> *Simply because they can’t cope with day to day living… You can find they are not getting their money if they aren’t signing on… So they are missing out financially* (Sam's social worker).

Young people who had recently left care and were learning to live independently often lacked budgeting skills and were tempted to overspend which put them at risk of accruing debt. Simon, who had recently moved from foster care to supported accommodation described coming to grips with money management:

> *It’s very hard to keep a track of money cos it’s like money coming in and you’re wondering what to do with it. But all that’s going on in my brains is ‘Spend, spend’ on something else.*

Some young people had accrued significant debts which they were struggling to repay from already tight financial resources. Tony was one young person who had accrued debts and arrears resulting in poverty:

> *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).

Connie's social worker also explained how care leavers can get into payment arrears and the importance of supporting care leavers to manage bills and debts:

> *Keeping up with payments, ensuring they are signing on in time so they are able to pay their charges... that would be a continual problem. We have quite a lot of experience particularly our young people with mental health problems getting into quite a lot of debt and not being able to see a way out... One young person was being taken advantage of by these companies who are making these agreements over the phone not understanding that this is a 19 year old who has an IQ of 55 exceedingly vulnerable to financial exploitation* (Connie's social worker).

With incoming changes to the welfare system, there were also concerns about how welfare reform would impact financially on disabled care leavers. For example, Danny, a young man with Asperger’s syndrome, was anxious about perceived threats to his benefits in the current austerity climate and his concerns were shared by his former carer:

> *He’s really worried about benefits … because of the welfare cuts... He’s concerned about how he’s going to live, how he’s going to pay the rent... It is a big issue for him* (Danny’s former carer).

SUMMARY

Care leavers were entitled to a range of benefits and accessed support from a range of service providers, friends and family members to access benefits and manage their finances. Whilst several care leavers were managing their finances well despite very tight budgets, many struggled financially. In addition, some young people were particularly vulnerable to financial exploitation from money lenders and family members. 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.

3.4.4 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, gaming and bowling. Several care leavers recognised the value of sport and keeping fit in terms of enjoyment and benefits to their physical and mental health:

> *I wouldn't cope without football. And… two hours walk a day* (Chloe).

However, most young people struggled to feel motivated to regularly engage in fitness activities:

> *I had been going to the gym and it was like making me feel better but then I just stopped going… I just kind of lost all motivation* (Norah).

Some young people had enjoyed social or leisure activities that had, unfortunately, ceased when they reached 18 years as they were only available for those under 18.

Many participants enjoyed socialising with friends and nights out in local bars and night clubs. Some young people who had previously engaged in substance misuse linked to this night life deliberately avoided these social environments and peers who had a negative influence on them as they had ceased their use of drugs and alcohol. For example, Norah, who previously had substance misuse issues, described her preference for quieter forms of relaxation:

> *I always regret going out... You get too much drink into you and then it's just like you are not yourself... I know everyone heads out but I love staying in now… I don't really go out as often.*

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. In such cases, young people pursued individual interests in the privacy of their own home. For example, Danny, who has autism and social anxiety, did not venture out in the community unless accompanied by someone due to fears of being victimised in his local community.

Young people's disability and mental ill health also impacted on their self-confidence and skills for engaging socially. Several young people with intellectual disabilities or ASD had directed challenging behaviours towards peers in response to social challenges which impacted negatively on social relationships. Several young people with social anxieties were also unsure how to negotiate peer relations and were fearful of social situations in further education, training or employment settings:

> *He knows socially he is inept in a peer group and that really lowers his self-esteem... He has never had a long term relationship with a peer and socially he wouldn't be outgoing at all so his Asperger's is a big thing for him* (Jake's social worker).

> *David will still have some difficulties with social relationships... social interactions will be his biggest thing. It was his biggest fear going to university (David's PA).*

Interestingly, some young people enjoyed their relationships with animals and generally taking care of pets. These young people spoke about the importance of their pets and how they found comfort in spending time with pets and confiding in them, as Danny explained:

> *Me and the dog are very close... cos I can tell her anything and she doesn't go and spout it... I don't really have many friends.*

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 participants. Johnny was a member of a youth club that he enjoyed attending however he hoped to secure a place at a closer youth club within walking distance to reduce his reliance on transport from his carer. Similarly, at the start of the study Simon relied on his carer to facilitate access to leisure activities and, as a result, felt that his social life was curtailed to a degree due to transport difficulties:

> *I don't get a chance [to go out with friends] much, cos I haven't really got the hang of buses.*

However, by the time of his final interview, he had successfully completed independent travel training and was enjoying travelling independently by bus to attend various social clubs and visit friends. The cost of transport and social activities could also be a barrier to participation in social or leisure opportunities:

> *I don't have very much money so I don't have the ability to go out there and do a lot. I would go out for walks* (Tony).

Social workers also recognised the importance of encouraging care leavers to stay connected with social/leisure interests and activities during their time in care and as they leave care:

> *It's the importance of giving our care leavers normal activities. I have another young man who has just recently come into the care system and he has normal interests… and slowly but surely as he has come into the care system he has lost those contacts… It needs to be somebody from outside of social services to come in and offer that because when he leaves care that's the support he going to go to.* (Laura's social worker).

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:

> *When he moves he'll be able to access horse riding... There's a lovely garden so he'll be able to come up for walks because there's enough space* (Declan's social worker).

Some care leavers had a supportive network of family members, carers and friends and most had at least one person to whom they could turn to for support. Some young people had several friends or acquaintances in the area in which they lived or at school/college or work. Others had large peer networks, however, simultaneously lacked a close friendship, as Tony explained:

> *I wouldn't have many good friends… I wouldn't have many friends that I would entirely trust.*

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

> *When I was a kid I was very awkward socially… 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... And I still do that sometimes today. 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).

> *She wouldn't be very good at making friends and she would have friends for a wee while and they'll slip… I feel it is a legacy of the past… and trust* (Chloe's foster carer).

Social workers also reflected on the challenge of establishing positive peer relationships for care leavers who had limited prior experience of consistent relationships:

> *Because all of their relationships with people have been fractured… there is no in-depth experience of… a relationship and mental health then that just caps it all... Laura knows that she hasn't got the confidence to walk into a room with other youngsters and be accepted. She is very, very self-conscious... She always sees the negative and… she doesn't develop and relationships. She develops fairly good relationships with adults but adults aren't going to sustain her out in that community* (Laura's social worker).

When there were risk concerns for young people or others, opportunities for social independence were more restricted. Sam, for example, was considered a risk to other young people during his adolescence which excluded him from many school events and outings and curtailed his peer relationships. However, as he explains during his first interview, he was being supported to make new acquaintances in his work placement and was regularly socialising with them outside work by the end of the study:

> *Working has gone well... I know a lot of people, a lot of friends now. Usually in foster care I didn't really have good friends because I wasn't really in a good relationship with other people... I just wasn't really a good person with being friends.*

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, when she also formed new friendships with peers at university:

> *We are really close.... cos I was in hospital I didn't really have school friends or anything like that. So it was good to get away and have some friends... Now I've also got like my uni friends.*

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:

> *He's been through children's homes and all that so we kind of relate in a way. Like if he's having a bad day, I would leave him be in his own wee zone. If I'm having a bad day he would just like leave me, so it's all good* (Jamie).

> *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.

Some young people had made deliberate choices to disengage with negative peer groups. For example, Norah regretted losing positive friendships when she befriended a peer group involved in drug taking and anti-social behaviour:

> *The biggest regret is I had a good set of friends and that all kind of broke.... I don't know why I was attracted to those ones that were drinking, going out every weekend… They were all drug dealers… but If they're getting you to sell drugs and you're taking drugs yourself you know they're not a friend... I am just trying to do good now. I am just trying to forget about the past and look towards the future.*

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 care leavers with mental health and/or intellectual disabilities:

> *The main worry I would have is just her potential for being socially isolated. She would have a tendency to be quite anxious about new social situations and meeting new people… in small groups and likes to have that wee bit of support as a backup... She still needs a wee bit of a push sometimes to get out and do new things* (Anna's social worker).

Likewise, Tony's social worker emphasised the lack of informal support from friends and family for some care leavers:

> *For some, there isn't too many people within their lives who are constant... They would have a lot of fleeting friends... There mightn't be many family members they're on speaking terms with... When you take out professionals, they're not really seeing anyone… So for those young people who feel isolated… there's a bit of concern* (Tony's social worker).

3.4.5 Personal Relationships, Vulnerability and Parenting

Young people discussed their experiences of personal relationships, both positive and negative. Respondents also highlighted care leavers' vulnerability to manipulation, exploitation and abuse as young adults. Finally, three young people described their experience of parenting responsibilities and the impact these had on their lives.

Personal Relationships

The majority of young people were single with only two young people in settled personal relationships and living with their partners for the duration of the study. These young people also enjoyed the support of their partner's family, which 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).

> *His family… are very, very supportive to me… because I have had a very bad complicated life, they sort of just took me into their family and understood what I went through* (Dawn).

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. Jamie, for example, discussed his reasons for not sharing his full care history with his girlfriend:

> *The relationship is good but I haven't really told her about my past… She knows a good bit of it but she doesn't know every detail… I just don't like talking about it… don't really want to scare her just yet… I don't really want to kind of make her feel sorry for me… but I've told her general stuff.*

For some young people, the challenge of personal relationships impacted on their own emotional wellbeing. For example, Rick, who had an intellectual disability, was engaged to a young woman who also had an intellectual disability. After his first interview, the relationship temporarily broke down and he suffered an acute period of distress and anxiety. During this time, Rick was supported by his foster carer, GP and mental health professionals who prescribe medication and provided a period of 24 supervision due to risk of self-harm. Similarly, Jamie's mental health was affected by a painful breakup, eventually leading to a suicide attempt. By the end of the study, Jamie was engaged to a new partner and planned to get married. Although Jamie's carer was pleased that he was settled in this new relationship, she was concerned that he tended to stop taking his medication when he was in a personal relationship which could lead to a breakdown if the relationship ended:

> *Every time he met a girlfriend… 'Oh I don't need the anti-depressants anymore'. And then if they finished down in the doldrums again… I had to explain to him 'Look you need to stay on them'. 'Sure I'm fine I'm fine'. But you worry* (Jamie's carer).

Similarly, other young people in the study had experienced symptoms of depression and anxiety due to difficulties in personal relationships. For example, Simon attended counselling sessions to help him to process his emotions when a personal relationship ended which also re-ignited painful memories of his past:

> *His mental health declined because … it wasn't working out… It got to the stage where he wasn't dealing with it very well and he broke down... The whole thing with him is his want to be loved and he does whatever he thinks he needs to do for that person to like and to love him… So he's been attending psychology again… mostly around relationships and then it's brought up… life at home, years ago... There was an awful lot of issues* (Simon's foster carer).

Alana, who had an intellectual disability, had two relationships during the course of the study and there were concerns expressed, mainly by her mother, about controlling aspects of these relationships. Alana, however, resented her mother's intrusion in her personal life:

> *X [boyfriend] is really nice… My Mother doesn't like him… He feels very unwelcome in this house.* (Alana).

Many of the young people had experienced negative relationships with three females having suffered serious domestic abuse from their ex-partners. Diane described regrets about the impact of this abusive relationship on her life:

> *The big mistake in life I can honestly say was my ex… When I came out of care … I was really on the ball… and then when I went with him it was all controlling. He just picked up where my mum left off… He hit me. He wrecked my car... I lost my job.*

Chloe had also experienced domestic abuse in relationships and her carer was worried that she was re-connecting with a violent ex-partner:

> *She gets into a number of relationships that are not good. She's had a couple of violent relationships where she has been physically hurt and her things smashed and stolen… She's very vulnerable. Chloe just wants somebody to love her and she wants a family of her own... It's very sad because at the end of the day it's all about love and companionship* (Chloe's carer).

Some of the young women who had experienced domestic violence from partners were still vulnerable to abuse. For example, although Diane had terminated her relationship with an ex-partner, she was still experiencing ongoing harassment from her ex-partner. Louise was another female participant who was struggling to end an abusive relationship.

> *We have broken up… That is quite a difficult situation basically because of his violence… We are not together 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.*

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:

> *There is a lot of domestic violence... A lot of our young people are very needy and you know predators are very tuned in to that… Then they're able to be used and manipulated. I think it's a lack of confidence also, self-esteem too... A vicious circle from one bad relationship to another to another to another… It's the need to be loved at whatever price. Even to be battered is almost at times for them a sign of love. 'Well he cared enough about me to hit me'* (Diane's social worker).

> *Her relationship with that fella was totally inappropriate... It would have been domestic violence and... we would have been concerned that she would have felt that that's all she deserved... just because somebody really liked her that she'd just be glad of that... She was so happy to have somebody like him... She could have been stuck in an abusive relationship* (Louise's social worker).

Abusive and/or controlling partners were not confined to the experiences of females in the sample. Some young men also revealed bullying in their intimate relationships. For example, during Jamie's previous relationship, his partner was instrumental in isolating him from his network of friends:

> *I lost a lot of them [former friends] through that relationship because I wasn't allowed to go out and socialise with them. And then she was writing to them and stuff to leave me alone.*

When Jamie ended the relationship he was harassed by phone calls and texts from his ex-partner. His social worker recalled the challenges of his previous personal relationship:

> *She would have been very dominant in the relationship… Anytime he tried to break up with her, she would have told him that she was pregnant and he'd have stayed with her... She ended up then going with somebody else... and they actually robbed him... He was getting quite a lot of intimidation in that estate off the back of what they were saying about him... It was just a toxic relationship... so it was a difficult period* (Jamie's social worker).

For young people living in supported accommodation with high levels of supervision, engagement in personal relationships could be under the surveillance and control of staff. For example, Belinda's fiancé also had an intellectual disability and she enjoyed speaking to him by telephone in the evenings. However, she was unhappy that staff in her supported accommodation placement withdrew these telephone calls when she displayed challenging behaviours:

> *My fiancé was so good to me… He is one of the people that has been very important to me… They are arranging to let me phone him every night if my behaviour stays the way it should be… I should be following how the rules are. So it all depends on me… When my behaviour is not good, they have to cancel the phone calls* (Belinda).

Vulnerability in Young Adult Life

The vulnerability of care leavers to manipulation, exploitation and abuse in the community after leaving care was evident from the interviews with young people, carers and social workers. Experiences of bullying and intimidation or abuse in the local community were common features of the care leaver narratives. For example, Danny, who had also suffered extensive bullying at school, recalled numerous traumatic incidents of abuse and violent assaults in the wider community which had a major negative impact on his mental health, social life and employment prospects:

> *Basically I have been bullied my whole life… at school and then people from the church down the road started bullying me… If it wasn't for that I would be having a job cos I done voluntary work in a shop... and once people found that out they were always in every day just to have a go at me… And the boss in there done nothing about it. That's what made me quit… Recently a guy stopped his car in the street honked his horn and shouted 'Get out of the town you f***ing retard'.*

Similarly, Dawn felt that her difficulty in re-engaging in college study was a lasting result of bullying:

> *I went to Tech... I actually left because I got bullied… I just wanted to get out, so just left. I was told to keep going back but I wouldn't... At the time like I didn't really feel comfortable around anyone after years of getting bullied quite a lot. So I just kept running away from things.*

Danny also highlighted a lack of confidence in the police service response to incidents of bullying of intimidation in the community:

> *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).

Some care leavers were aware of their vulnerability to exploitation and developed strategies to protect themselves based on previous experience of manipulation or abuse. For example, Tony felt he learnt a valuable lesson from an experience of lending money that was not repaid:

> *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 friends or people I thought were friends than I lost.*

Some care leavers who had moved to independent living were targeted by other young people in the same housing development 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 putting their tenancies at risk due to anti-social behaviour:

> *A fella… that lives upstairs, his electric wasn't working so I let him stay on the sofa and he just hasn't left and I'm just too nice a person to tell him to 'Get to f***'. And then my girlfriend is living with me too and I don't think it's doing our relationship any good... I need my own space* (Jake).

As mentioned earlier, carers and social workers were also concerned about financial exploitation of several disabled care leavers by family members as they re-united when the young person left care. For example, Charlie's social worker was concerned about his return to live with birth family who wished to have control over his own finances, however, they were unable to take any action to protect him:

> *He went to move in with his brother and he hasn't done so well since... He is running round with a bad lot and is probably being used by others to their advantage... We'd requested a vulnerable adult meeting... There weren't any kind of major interventions as a result* (Charlie's social worker).

Charlie disengaged from the study and all services after the first interview, however, his social worker remained concerned about his vulnerability in the community and risk of financial exploitation as a young adult.

Since moving to more independent living, Simon, who had an intellectual disability, was engaging more in smoking, drinking alcohol and socialising in local nightclubs. Simon's former carer felt he did not fully understand the dangers of living in the community, leaving him more exposed to risks. During his own interview, Simon described feeling unsure about how to interpret social cues and keep himself safe in challenging social situations:

> *There's this person... He was giving me the looks saying 'Get away'. And I went over and said 'What's wrong?'… It was probably me who started it. I should have just left it... and he said he wanted to kill me or something... I didn't know what to do in that situation.*

Following this incident, he had received support from a mental health professional who advised him of strategies and techniques to employ when other people are verbally or physically threatening in public.

Chloe also felt unsafe both in the area she was living and also within her own apartment block which was being used by other tenants for drug-taking and other anti-social behaviour. She described the events leading to her ending this tenancy:

> *When I was leaving I had to go to the housing executive because the fella across from me threatened to beat the head of me for absolutely no reason… It was a full on party all night... The doors were left open and they were just running in and out of each other's. And the housing executive came out with the police... and I just handed them their keys.*

Sectarian abuse also affected a few of the care leavers. Jamie discussed how his involvement with his ex-partner rendered him vulnerable to sectarian intimidation and violence in the local community:

> *It was a big protestant area and I was going with a catholic at the time… They didn't take that too well… When I was walking up the town with my friend they were throwing big stones and stuff.*

The violence towards Jamie escalated until an incident culminating in his admission to hospital for injuries sustained during a sectarian attack. Jamie moved away from his home town soon after, in an attempt to move on with his life without threat of violence and intimidation:

> *We would walk up the town and they would call us names and stuff... Then one night they came around… just started hitting me and stuff... They only broke my nose. I had to go to hospital to go get it fixed.*
>
> Interviewer: So was it then that you made the decision to move?
> *Yeah. I didn't want to get that every day of my life. I wanted to get on with stuff and do my own thing.*

Some social workers commented on how disabled care leavers could engage in risky behaviours to help them become accepted into a negative peer network:

> *Learning disabled young people who have maybe a smaller peer network and have to make themselves available to feel that they do have friends and that can lead to further exploitation* (Connie's social worker).

There were also concerns regarding sexual exploitation, including mobile and online safety, often linked to engagement in substance misuse and negative peer networks. Social workers were particularly worried about the vulnerability of young people with borderline impairments in the community:

> *Those with a mild disability can nearly present as more challenging in terms of they don't view themselves as having a disability... and reject the support... They get involved in relationships or this whole sexting thing… they don't understand the vulnerability they've exposed themselves to... you just worry for them* (Paul's social worker).
>
> *You often have people who intellectually may be above the threshold of the 70 IQ but… tend to be very vulnerable young people. I think they are much more likely to be sexually exploited… They're also very open to financial exploitation, often by birth family members who maybe have ulterior intentions...* (Charlie's social worker).

However, attempts by social workers to intervene and protect young people were often resented, as Susan explained:

> *They think you are putting yourself at risk… of sexual exploitation... and they get people lifted and all... Sometimes I take herbal [legal highs]… but you feel like a villain… You walk to the shop and you get accused of prostituting yourself for herbal.*

Social workers recognised the rights of care leavers to make their own choices but sought to balance these rights with their concerns about the young person's limited insight into potential risks. Direct work with young people based on a sound working relationship was viewed as key to helping care leavers understand risks and keep themselves safe:

> *She has very little insight into the concerns that the professionals would have for her... She's sort of like 'right I've heard it all before'... She would really minimise the concerns... Her whole perception is that all men cheat and are also physically violent and it's about talking to her about 'No that's not actually the reality and that's not something that you have to accept necessarily in your life'... but you're trying to do it in the sensitive way* (Susan's social worker).

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 is essential and young adults with intellectual disabilities who are transitioning to more independent lives need ongoing access to support as they negotiate personal relationships.

Whilst there were genuine concerns about the risks posed to some disabled care leavers, there were also indications that those with more severe levels of impairment were over-protected. Linda and Belinda were two young women with intellectual disabilities who felt restricted by staff regarding their freedom to enter into intimate relationships. Throughout her three interviews Belinda spoke of difficulties of being allowed to have contact with her fiancé (who also had an intellectual disability) and having their contact monitored and supervised. When asked about her knowledge of safe sexual relationships and birth control, Belinda's focus was on what other people had told her regarding its potential effect on her health:

> *I'm not allowed pregnancy… because I'm ill… My mummy [said] she think it's a bad idea… in case your pregnancy might hurt the same time you have seizures… You might have to live in hospital, stay away from your man* (Belinda).

Belinda's social worker was mindful of the need to consider her capacity to make informed decisions about personal and sexual relationships:

> *There is always that high risk factor because she doesn't have a full understanding of what the consequences could be to her actions and... obviously there is risks there for her… So it can be a challenge managing that and making sure she is safe and isn't taken advantage of... She's so vulnerable and you could see how easily she could be exploited* (Belinda's social worker).

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. For example, Connie's social worker was very concerned about her understanding of safe and respectful sexual relationships but intervened at her own pace to educate and support her rather than prohibit personal relationships deemed to be exploitative.

A few social workers, however, also commented on the impact of their own attitudes towards sexual relationships for young people with intellectual disabilities and their lack of expertise on how to discuss this issue with disabled care leavers:

> *I think people with a learning difficulty are very vulnerable especially within relationships... It's an issue people find difficult bringing up with all young people anyway, you know, sexuality etc. but I suppose with a learning difficulty we all maybe find it more difficult… There's a lot of assumptions… All of us can be guilty of forgetting that side of people when they have a learning disability* (Louise's social worker).

Whilst much effort was made to safeguard disabled children during their time in care, when young people turned 18 years old and were no longer within the remit of child protection law, a more limited range of actions was available to protect them. Team leaders described urging their staff team to consider disabled care leavers as vulnerable adults to ensure they were adequately protected from harm:

> *Safeguarding with vulnerable adults is key and one that I have to drum into staff is that our 18, 19, 20 year olds with the mental health and with the learning disabilities are vulnerable adults and not just care leavers so we very much have to be aware of that* (Connie's social worker).

Vulnerable adult teams, however, tended to be more reactive than preventive in their approach to safeguarding and rarely co-worked on cases relating to adult care leavers deemed to be at risk of exploitation or abuse:

> *We've tried to make that link with the vulnerable adult team... You're actually asking the vulnerable adult team to be part of the risk management meeting but they'd say 'Everything you are doing is fine'... Their team is quite a broad spectrum* (Norah's social worker).

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. All availed of 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 let me live with her… She just helped me out a lot. And then I finally got the hang of it myself… and the course I'm doing is brilliant. It helps me. He goes to a wee crèche and I 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).

In all three cases, their ex-partner's family and their former foster carers also played key roles 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).

Social workers 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 care leaver and their young child:

> *When I can't get Joanne and I would become slightly concerned… I am able to lift the phone and they are able to keep me updated, as to how she is doing and how baby is doing... They are there to ensure his needs are being met, emotionally and physically* (Joanne's social worker).

In one case, child protection or care processes were not in place and the young parent was heavily supported by her 16+ social worker and former carers. 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 access to emotional and practical support from family and child care services. For example, Jack welcomed the financial support provided by children's social services teams in times of emergency:

> *The Care Order has its benefits... like if I ever run out of oil and I'm really, really stuck they will… get me a drum of oil just to tide me over.*

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… It's about making sure he's alright… but I want him to have a normal life without having a social worker... I don't really need anything from them* (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:

> *The social workers assumed I was going to be like my parents which I am not... 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).

> *They [social services] think that because of our past we are going to do that to our children... She was in care, she's this and she's that... And it's not like that. We want a better life for our children than what we have been through... I'm trying to be a good mummy but it's like they're not letting me be… 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… 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. For example, in Jack's case, his PA informed children's services about their concerns about the impact of his repeated house moved on his child's wellbeing:

> *I said… 'I'm sharing with my line manager and the social worker that it's not healthy for this child to be doing all these moves'… He went ballistic and he complained about me… but we had to report that… and then he was kept on the child protection register for a while longer which he was obviously very upset about but we had to put the child first in that situation* (Jack's PA).

By the end of the study, even though he had proven his ability to provide adequate care for his child, the 16+ team were still clear that the case should continue to be monitored:

> *I know it can't go on forever but it would be important that the children's team stay involved for a while for his child's sake to monitor… for a while after the 16+ service is finished with him… I would be the fearful of it all falling apart for him and then maybe losing his son* (Jack's social worker)

However, when 16+ social workers had established trust based relationships with parenting care leavers (as in Joanne's case) they were best placed to support them in their interactions with child protection teams and advocate for their access to a range of specialist support that would enable them to parent effectively. For example, Norah's social worker recalled another case where she had intervened early in response to a care leaver's experience of post-natal depression with a positive outcome:

> *I have a girl who has a baby and she had really significant mental health difficulties... She had suffered from post-natal depression… She was able to trust me and speak up and say 'I'm actually feeling really crap' and it didn't result in her baby being removed… Actually I met with the baby's social worker at that time, reassuring her too, you know, 'Just because you're feeling low doesn't mean that we're going to come in guns blazing and take your baby from you. It would be a bigger worry if it went untreated'… And now she's doing really well with her baby… Trust and good relationships are key and actually consistency in relationships too* (Nora's social worker).

The experiences of the three parents in the study highlighted the impact of their parenting role on their own lives in terms of their mental health, the stability of their own lives and their ability to continue with education or employment. For example, Joanne experienced post-natal depression and resumed taking medication:

> *After he was born… I just crashed… and that's when I had to go back and ask for meds… and then they sent me back to the mental health team… I was quite badly depressed there a few weeks back so they've been changed recently and they're starting to kick in now.*

Sara expressed how she loved for her child but regretted, to some extent, becoming a parent at such an early age before establishing a settled life and career for herself:

> *I love being a mummy but I would rather have waited until 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).

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, as Sara's social worker and Jack's PA commented:

> *It is raising quite a few issues for her to do with her own experience… her own memories and history of what that was like for her... Some of the support services the baby's social worker is trying to put in… are local and she would have used them herself as a child so she finds that quite difficult* (Sara's social worker).
>
> *There was interesting things happening in the whole process… even changing the baby… The smell of the dirty nappy brought him back to his own childhood about him being left in dirty nappies… A lot of flashbacks to his own childhood… but he has done brilliantly… He's a good parent* (Jack's PA).

Managing parental responsibilities and education was also a challenge with all three parents withdrawing early from college courses. Jack cited parenthood as the main factor that led to a temporary withdrawal from college while his child was young. Similarly, Joanne's grades lowered during her pregnancy and, as she struggled to keep up with college classes and coursework in addition to working part time, she withdrew from her course.

The leaving care policy that care leavers should be supported by 16+ services until the age of 21, or 24 if they are in full time education, affected the parents in the study who were forced to withdraw from education. These parents had plans to return to study when their children reached school age and Care Orders had ceased. However, by that time, they would have exceeded the age limit for ongoing support from 16+services. For example, Jack's case with 16+ services closed during the course of the study because he was 21 and no longer attending college. He hoped to return in the following year when his son began nursery but was aware he would not be able to access support from 16+ services at that stage. He explained:

> *When you are 21 they close it unless you are in full-time education. I think that is wrong. That is like saying if you go to Tech you can keep us, but if you don't we don't want you… You have reached the end of your time and we are casting you off now… 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... I failed the last year of my course so 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 child care, not on my budget* (Jack).

SUMMARY

Young people enjoyed varied social interests, however, engagement in social activities could be impeded by mental health and disability related needs, limited independence, bullying and risk concerns. Therefore, access to independent travel training and appropriate supports were important. Negative experiences in and pre-care also had a lasting impact on abilities to form and maintain friendships, with ongoing issues relating to trust and poor self-esteem.

Most care leavers were single or in short-term personal relationships with only a small number being in settled relationships with partners. Several young people had experienced abusive or manipulative relationships. Young people with intellectual disabilities who were living in adult residential placements had high levels of staff supervision which restricted their opportunities to engage in safe, personal relationships.

There were fears about the vulnerability of care leavers to negative peer influence and financial or sexual exploitation. The need for more preventive programmes for disabled care leavers was emphasised in order to develop their awareness of different forms of exploitation or abuse and to develop effective safety strategies.

The three young parents in the study had full custody of their children and were supported by social services, extended family members and former carers. Two of these care leavers felt that their parenting was under tight surveillance which discouraged them from engaging with child care and protection services. In other cases, care leavers had trust-based relationships with 16+ social workers and had been able to share concerns for their wellbeing and, subsequently, access early, specialist intervention. Being a parent impacted on several areas of the young people's lives, including their education/employment and their social lives.

3.4.6 Identities, Self-esteem and Stigma

During interviews with care leavers, social workers and PAs, key aspects of the identities of care leavers often came to the fore including issues relating self-esteem and confidence. As young people moved on from care, they often needed to revisit past experiences and re-negotiate relationships with birth family. This section will explore these identity issues (disability and mental health related identity issues have already been explored earlier in section 3.1) and also report findings in relation to how care leavers experienced stigma and discrimination as they moved into their adult lives.

Self-esteem and Confidence

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. For example, Jack's social worker explained:

> *A lot of young people don’t have the ability or confidence that Jack would have had... His confidence has come out of survival... sort of 'I’m not going to let this woman, mammy, destroy me anymore'... It was more a sort of defence, a survival for him that he has developed that confidence* (Jack's social worker).

However, most care leavers had low levels of self-esteem and confidence which impacted on their daily lives and progression into adult life:

> *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).

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. For example, Susan, who had spent much time in secure care settings, was planning to move into supported accommodation towards the end of the study and, although she was still being supported by several agencies, she remained anxious about the prospect of independence:

> *It’s gonna be hard because I’m so used to having people round me all the time, looking after me… Someone to fall back on all the time... But I have to get used to it* (Susan).

Care leavers with poor self-esteem could be hardest to reach by service providers as they were unwilling, or lacked motivation, to engage with services. In these situations, social workers felt that care leavers' self-esteem may improve if they were willing to engage more with services:

> *If she allows support services in, we could look at doing something for herself because I do think her self-esteem is quite low... She is quite stressed and quite anxious* (Sara's social worker).

Low self-esteem pervaded many areas of care leavers’ lives, particularly their ability to form and maintain friendships and personal relationships. For example, Tina discussed how she felt negative about the prospect of meeting a new partner due to her low self-esteem and poor body image:

> *In terms of my self-esteem… I think it will be hard… In terms of my body image I don’t feel that I would want anyone to see me.*

Chloe’s carer commented on how poor self-esteem and trust issues affected her ability to make friends:

> *Chloe wouldn’t have a lot of self-worth at times. And she would look down on herself… ‘Why would they want to be bothered with me?'* (Chloe’s foster carer).

However, there were examples of improving self-esteem from care leavers. Diane felt her confidence was improving as she recovered from an abusive relationship:

> *It was such a rough breakup… It did really mess with my head. I had no confidence… doubting myself... even social skills as well. My head’s haywire, but it is settling down. The longer I am doing well without him, the more I am getting back to myself.*

Likewise, although Tony was not involved in a relationship, he was feeling more confident by the end of the study about interacting in social settings and with potential partners:

> *There is no current relationship standing although I certainly feel a lot more comfortable around the opposite sex now. I wasn’t really myself so I kind of secluded myself from that.*

Jamie had struggled with everyday social interactions and previously relied on his foster carer and 16+ professionals to liaise with various agencies on his behalf, however, by the final interview, he had become more self-sufficient in terms of independently managing his own affairs:

> *It's kind of hard. I'm an adult and I have to do everything myself... I know it sounds silly, but I can't believe I actually made that… appointment about the depression. And then having to tell them how my sleeping was and how I was feeling and all that… I would have been relying on others too much I'd say. I'm getting there.*

Jamie's carer also commented on Jamie's improved self-confidence:

> *He's amazing for what he has been through. You know there were times in his early teens you would never have dreamed that he would be the confident fella that he is now* (Jamie's carer).

Social workers also commented on how, for some care leavers, successful foster care placements had bolstered a positive sense of belonging but could also restrict their social independence and confidence:

> *Her foster mum would be quite protective of her... She's getting to the age now where she does want to be a wee bit more independent but sometimes still needs a wee bit of a push to do that because it's just easier for her to be at home... I would just love to see her being a wee bit more confident socially* (Anna's social worker).

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 this aspect of their identities. At times, this required a careful balance of empowering young people with mental health or intellectual disabilities to develop more positive self-esteem whilst also ensuring they were realistic about their future options:

> *On one hand you are trying to build their self-esteem and their confidence and identity... but then it's about... the real world and what is achievable for the young person and trying to communicate that to them... without damaging their self-esteem and it's not easy... You get some young people that don't see their worth, they don't see how capable they are... Some have their limitations set so low... whilst others can see their potential and their capabilities... and a lot of is to do with low self-esteem... and it's about building that back up again over time* (Joanne's social worker).

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. Many felt a stigma relating to one or more of these identities and some had multiple experiences of discrimination.

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 example, when Lorna moved out of her kinship placement during the course of the study, she felt she was like any other young person leaving home and moving to independent living for the first time:

> *I kind of see myself just sort of leaving home, just flying the nest. Doing something that everybody has to do at some point. I didn't see myself as a care leaver… just sort of seen it as leaving home.*

Alana also lived with an aunt and did not identify with care leaver status:

> *No I don't see myself as a care leaver… I just don't think like that… because it was family it didn't seem like care.*

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?… Like what do normal people do?… I'd probably be classed as institutionalised* (Jake).

Revisiting and making sense of the past was a common feature of the lives of care leavers. 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. Many participants commented on how people judged care leavers negatively according to common stereotypes:

> *People tend to think children that have come from care backgrounds are going to be trouble makers… they already have that kind of a wall up... I think that that's very bad... I think there needs to be a lot more realisation that there are people that just want to be treated as young people* (Louise).

> *They seem to tar us all with the same brush. They all think because we were in care that we're causing trouble… 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 I don't let it get to me now because I don't really care who knows anymore. It's not something I should be ashamed of... 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, such as Jake, felt a deep sense of injustice that, because of very negative behaviours of a small number of young people in care, 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… 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 they're thinking negatively unless they've been through it themselves... 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 didn't do anything* (Joel).

Similarly, one social worker described a case where the police had not treated a care leaver fairly, leading to an official complaint:

> *We had a situation with a young person who had made an allegation of rape and how the police managed that case was atrocious... Just because this young person is a care leaver she shouldn't be treated any differently but it was a severe neglect of duty as far as we were concerned and we supported them and a complaint was upheld* (Lorna's social worker).

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).

In addition to care leavers being pitied or viewed as trouble makers, participants felt another common assumption attributed to care experienced young people was that they would inevitably have poor mental health or substance misuse issues:

> *It's like a stereotype that everybody in foster care has a mental health problem* (Chloe).

> *Most people think people that have been in care are complete whack jobs with needles sticking out of their arms* (Jack).

Social workers were also 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. Some wished to keep their past lives in care hidden from new friends or partners and, as a result, disengaged from social services due to a desire to move on with their lives and disassociate from care related services:

> *For some young people leaving care lifts the stigma attached to them, you know, they're no longer in care so... the control rests more with them in a sense that they don't answer their door, you know, they can make those choices* (Jamie's social worker).

Simon hid both his disability and care identity from others:

> *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... You don't want to tell everybody that you have special needs or anything cos it's nothing to do with them... It doesn't matter. I keep both disability and being in care to myself.*

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 the 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... cos at the end of the day everybody has their issues and problems. Just go ahead and do 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 that being care experienced directed them towards a career path focused on helping 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...* (Louise).

Making Sense of Family Identities

For most young people, making sense of their family relationships was a core aspect of their identity:

> *Family dynamics is a big issue for him in terms of trying to get his own self-identity out of that… who he is and what level of contact or acceptance he will have with parents* (Jake's social worker).

Many care leavers struggled to come to terms with negative family relationships and dynamics which persisted as they transitioned into young adult life, sometimes blaming themselves for poor familial relationships. 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 experiences:

> *It is more difficult for young people with Asperger's or a mental illness or learning difficulties. A lot of the times those young people struggle to understand their background and then it's that whole thing of trying to process that… who I am and why I entered the care system and the limitations in terms of what the family can offer them* (Jake's social worker).

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… My relationship now with my parents… is still difficult* (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 things. I like to know these things. But in a way in don't and it upsets me to know it* (Simon).

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, although social workers were often concerned about how young people would react to case file content about their past experiences:

> *It'll always bubble below the surface and at times... There are things from his childhood and his time with coming into care which affect him…. At times he has been very keen to go back over it. My own feeling is I'm not sure how beneficial it will be to him* (Tony's social worker).

Whilst 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, 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).

The challenge of negotiating ongoing negative family relationships took its toll on the emotional wellbeing of care leavers with some experiencing a deterioration in their mental health due to conflict with family members:

> *Family issues are a big thing for her… and still haven't really been resolved… She struggles with her past definitely... Her mental health would then be part and parcel of that you know, low moods, anxiety* (Chloe's social worker).

Even for those young people who left care and returned to live with family members, the dynamics of their family relationships continued to impact on the emotional wellbeing of young people:

> *You become an adult and wish to return home and don't know how to manage that… You're living with your family who were unable to care for you... It's an awful lot even just in terms of how they manage their own emotional needs* (Declan's social worker).

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.

SUMMARY

The few care leavers who did not feel stigmatised in relation to their care experience were those who had enjoyed long-term foster or kinship care placements since young ages and were fully integrated into their foster families. The majority of care leavers had experienced discrimination on the basis of their care history as they sought tenancies and employment and as they engaged with various community services. The continued feeling of being stigmatised negatively impacted on the self-esteem of some young people 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 was part of who they were and gave them particular strengths and insights that would enhance their future lives and careers.

The majority of care leavers continued to negotiate challenging family dynamics as they left care, including those who did and did not return to the care of birth parents. As care leavers moved on with their young adult lives and some became parents themselves, they revisited their own child and adolescent experiences, the reasons they came into care and the meaning of family for their own self-identity. Some young people were able to establish a place for birth family members in their lives, distant or close, whilst others came to a realisation that birth family relationships were likely not improve and ceased all contact.

3.4.7 Hopes and Fears for the Future

Much of this report has focused on leaving care experiences, however, young people interviewed were also keen to discuss their futures. This section explores care leavers' hopes and ambitions for the future as they moved forward in their young adult lives. In addition, young people shared their worries and concerns for the future.

Hopes and Ambitions

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. Some young people with intellectual disabilities expressed desires to move to eventual independent living but held doubts were held, either by the young people themselves or their carers, as to their aptitude for successfully coping with the demands of independence:

> *I would like to go to my own flat if I could because I can't have staff all my life. It would be good. But I don't know yet... if I can't then, I'll just probably stay here* (Sam).

Young people also expressed a range of ambitions for education, training and employment. Those who were engaged in educational programmes were looking forward to gaining qualifications, further postgraduate studies and securing employment. Going to university and, for some, leaving NI to study at university elsewhere was an exciting planned move. For example, Lorna looked forward to living and studying away from home with a mixture of excitement and trepidation:

> *University is just my focus now… I have a fear of me actually moving out of the country away from away everybody but it's more excitement for me rather than fear. It's sort of that I'm now able to go and 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).

Some care leavers were keen to pursue careers as social workers. They felt they had an aptitude for this role, derived from their own care experience and natural empathy for young people in care:

> *I just want to go uni, get my social work [degree] and I want to go into residential care work… because I know what it was like… I've been through it. I know what they're going through, and if that gives them a connection with me and helps them that bit more so be it. I just want to help people, the way I was* (Joanne).

However, some young people were acutely aware of the challenges of securing future employment. Jake, who was struggling to find a job, emphasised the importance of gaining work experience:

> *I desperately, desperately need a job… They're very hard to come by… After two years of unemployment and only two interviews and applying for countless jobs I'm not getting anything... There's only so much experience you have and that's all they look for now is experience. But how do you get experience if you can't get a job?*

Young people who were living relatively stable lives in terms of accommodation, further education and solid support networks, were more likely to view their futures in a positive light. For example, Lorna was optimistic for her future outcomes, while simultaneously realistic that dips in her mental health could be overcome by drawing on support:

> *Onwards and upwards as I say. I'm just going to try and continue on the upward streak that I'm on and if I do hit any sort of bumps in the road along the way, I will ask for help. You know I will tell somebody that I need some help* (Lorna).

Simon summed up the importance for a positive outlook on the future:

> *Tell them [other care leavers] don't be afraid of your future. Just think positive things that you want to achieve in the next couple of years… It's like a mountain. You just you think you're down*

> *at the bottom but eventually if you keep thinking positive things, eventually you'll think you're at the top. I'm not at the top but I think that I'm near the top.*

Jake, however, had a bleaker outlook and represented those young people who were not progressing well in their transition from care with little hope for the future:

> Interviewer: What might happen between now and the next time we see you?
> *I could be dead.*

For some, ongoing struggles with mental ill health or addiction meant that the main priority was to have a healthy, settled life. For these young people, an improvement in their mental health or ongoing abstinence from alcohol or drugs was the key objective:

> *I hope I don't go to prison again… Stick to the job and just stay away from drugs... because I am a good worker and I think the drugs just kind of make 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 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 like what happens if I move out into the community and I forget to pay my bill for like where I'm living, my rent?... If I do anything wrong with it, but people keep telling me that it's ok to make mistakes* (Simon).

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).

Similarly, Norah expressed worries regarding her ability to cope when the emotional support from her 16+ social worker, with whom she had developed a close relationship, eventually ceased. For most 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).

For those who were struggling to maintain tenancies and manage on a low income, the main fear was becoming homeless and losing benefit entitlements. In contrast, Tony, who had experienced disrupted education and had limited qualifications and job opportunities, feared he would fail to escape the benefit system:

> *I am worried that I am going to be stuck on the dole for the rest of my life… I do not want to end up like that because that is something I would view very negatively* (Tony).

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:

> *My family are not getting any younger… what if something happens to them… You can't overlook all their wrong doings… If they were really sick I probably would get involved but it's hard to know what to do* (Louise).

> *Well they [kinship carers] are getting old so they are going to die soon. So that will be another kind of support gone. It will be hard.*

Carers also worried about young people who were socially isolated and the loss of their small support network through bereavement:

> *The big worry is that he doesn't have enough young people of his own age around. And I've explained to him, that… I'm old now. I'm not going to be around for much longer... I'd hate to see him as a loner in the community and with no-one there to really support him. Social Services are only going to be around for him for another couple of years… So he's going to feel the loss of that… There isn't at the moment anything that he can relate to in the community or anything that can relate to him.… He needs someone there for him in the long term* (Danny's former carer).

Other worries held by carers and parents of care leavers with more severe impairments and challenging behaviours related to these young people not reaching their full potential in life.

SUMMARY

Care leavers had varied ambitions for their future lives relating to family, relationships, housing, educational and employment. Unfortunately, some were already 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 tended to reflect these barriers and how they would cope when support previously received was reduced or ended. There were, however, examples of young people were who progressing towards their career and independent living goals and had clear plans for their future lives.

3.5 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. This section of the report will describe their use of this range of services and explore some of the challenges for care leavers in terms of access to appropriate and timely support as they moved into their young adult lives.

3.5.1 Sixteen Plus 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 process:

> *The ideal way it should work is that they're introduced to our service from 15 and a half... they get to maybe meet the worker at the LAC review. We get the files and... the LAC social worker will come and discuss the case with the new social worker and there's usually a joint visit* (Sara's social worker).

> *For a while there, young people were delayed coming over to the service because we simply didn't have the capacity* (Sara's social worker).

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 they 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:

> *There's no requirement for a social worker beyond 18 so we would rarely provide a social worker and a PA to a child with a disability because they already have a social worker. Now some disability teams really rail against that… saying they need a social worker from the 16+ team because there are so many child care issues... I'm sure 16+ teams are just as bad going it's primarily disability issues and they're the experts on that... but more often than not, because you're not going to have two social workers, the disability worker takes it on and we provide a PA... Disability provides the social worker because that's a statutory responsibility and we provide the PA* (Charlie's social worker).

Interestingly, the same issues did not seem to be applied to care leavers with mental health needs when 16+ services assumed lead responsibility for the case:

> *Where it's mental health, we lead... if they're involved with mental health professionals, they do what they do but they're not managing their overall social work case... They are only dealing with mental health issues* (Charlie's social worker).

Some care leavers indicated that there was a reduction in 16+ support once they had made the transition from care, particularly after their 18th birthday. Jamie commented on the decrease in 16+ services after he turned 18:

> *It's a different ballgame to whenever you were under 18, the services they would have given you. But then whenever you turned 18 it was kind of like you know there wasn't as much.*

Jack also observed a lack of PA support once care leavers turned 18 years old with those most in need prioritised:

> *They [PAs] are not a help any more once you turn 18. There is no financial support... But it's not just the financial support. It seems to be there's that many young people they just don't have the time for you... The more messed up you are, the more help you will get off them... My social worker, I don't see... I've said a few times and the words I'm getting are their budgets are cut* (Jack).

Similarly, Joel noted a stark reduction in support post 18:

> *The 16+ team would need to be more involved with the kids from 18 – 21… way more involved. There is definitely not enough there* (Joel).

Social workers concurred that there was a stronger focus on care leavers aged 16 to 18 years 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:

> *When they are looked after up to 18 we have responsibility to see them monthly... so in leaving and after care we wouldn't have as much contact... Often you find when they turn 18 it's whatever level of contact the young person wants* (Alana's social worker).

Some social workers were dissatisfied with this approach as they felt that those aged 18 to 21 years were often experiencing major transitions and required more support from the 16+ team, particularly care leavers with mental health and/or intellectual disabilities:

> *We have statutory responsibility 16-18... so our 18-21 year olds who we used to be able to spend time with are totally neglected because we have to focus all our attention on the ones we have statutory responsibility... It does make a difference for the outcomes at 21 especially for the likes of learning difficulties... They need a lot more support... and input 18-21* (Louise's social worker).

There was also some concern that PAs now assumed more responsibility for care leavers aged 18 and over as they had less contact with social workers at this stage:

> *When the social worker took over LAC responsibility at 16, they were restricted a lot by what they can do with the over 18s not by their choice purely because of time constraints... Social workers are feeling devastated about it cos they set out to build relationships with these young people from 16-18... Post 18 their circumstances do change or they have moved out by themselves... That's where the social workers as well as the PAs want to be involved, that's where you are going to have maximum impact... Now you are down to one worker... the PA... the PAs are very good but you go to somebody and you say you're a PA 'What's that?' You go to somebody and you say you're a social worker for the young person, it does have a certain degree of clout which means sometimes you get a quicker response in relation to the need of the young person* (David's PA).

However, one social worker noted the need to signpost older care leavers to alternative sources of support as, due to high caseloads, young people need to exit the service to allow capacity for new cases coming in.

For most young people, 16+ services withdrew as the timing of their 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 a placement move or mental health crisis. For example, Simon had limited contact with his 16+ social worker at the time of the first interview, however, by the second interview she was more heavily involved in a co-working approach with adult disability services as he prepared to move into supported accommodation. Social workers also highlighted cases where more intensive support from various team members had been put in place:

> *I have a 17 year old who has moved home from a residential unit. She has a learning disability and I insisted she has a PA and an intensive support worker so she has a co-worker working with me because she was aggressive towards me... plus she has a befriender so we have got 4 workers in there… because we have to work in two's each week* (Laura's social worker).

> *We have young people who are struggling… and sometimes there is a full service approach... If a young person presents in crisis on a daily basis... We have a rota going on to support young people who have particular mental health needs and people calling for them every evening so we go the extra mile if it is someone with particular needs* (Tanya's social worker).

Some care leavers were keen to cease contact with the 16+ service if they felt there were no further services they could avail of or they no longer needed their support. For example, Diane had aged out of the service and felt there was limited value in continuing with the service:

> *They closed my case… I'll be 22 soon… There's no more support they really can give.*

A further reason for exiting 16+ services was a desire to embark on a more independent adult life:

> *I told them 'I'm leaving yous... new start, new life'... They wanted to keep the case open and I says 'No'... Then I'll be able to go out and do my own thing without them asking about it* (Alana).

Other care leavers who had ongoing needs made the decision to disengage from 16+ services themselves either because they did not have positive or consistent relationship with staff or did not see any advantage of having access to the service. However, on reflection, most young people emphasised the importance of staying in contact with 16+ services. 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 they offered:

> *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).

For a small number, disengagement was related to their deteriorating mental health or engagement in risk-taking behaviours. Early disengagement from support services was concerning in cases when young people had ongoing mental health needs or were deemed to lack independent living skills or be at risk in the community. In these cases, 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… I have young people that just have not responded to me for months... I really struggle with the fact that these young people are identified as needing a social worker to the point where they cannot close until their 21st birthday and we are not necessarily setting eyes on them or hearing anything about them* (Tina's social worker).

> *Some of our kids want nothing to do with anybody post 18 including ourselves... but we remain open. Until at least 21 they can come back to us at any stage.... It is about respecting the right for them to be able to choose that because they are adults* (Lorna's social worker).

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. As making multiple visits to young people who were not responding required additional time, social workers felt they needed to prioritise active cases and the longer-term 'keeping in touch' role was often undertaken by the PA:

> *If there's somebody who is very high risk, there's always a social worker involved... You still have ones on your list where... the PA maintains contact but you're still the named social worker and if anything is needed financially or if there's any issues the PA would come to me... but if there's no issues she would just keep checking if everything is going ok* (Linda's social worker).

Several young people recalled how the 16+ team used incentives to encourage them to engage with services, for example, access to financial entitlements. Indeed, social workers indicated that they tried a range of such strategies to encourage young people to stay engaged with services:

> *I've got a young lad turned 18 and he shook my hand and says 'This is the last time I'm seeing you'... There's different techniques I can use to try and get back in with him... The young people*

> *are entitled to take money from their junior ISA account or... continue to save. So that's always a great tool to use post 18... to keep them working with you* (Danny's social worker).

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:

> *You have to persevere whenever you first meet a young person sometimes… They were so fed up and knew they didn't have to have a social worker anymore. But if you persevere a wee bit then they see the benefits of it and it's fine... Most of our young people engage... They get to know you and then by the time they're 18 they're actually engaged well... It's about leaving that open so it's not forced upon them* (Louise's social worker).

> *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).

> *If they're over 18 then, it's up to the young person whether or not they want to engage but we find in this team that 99.9% of them do, as much as they say they won't. So we keep trying, you know. Over 18s for example, we will, even if they're not engaging, we will constantly ring them, send out letters... what you find is they actually turn round and go "They're not giving up. They actually do care. They want to be involved with me" and they'll come back to us. We just keep trying and nine times of ten they'll come back to you* (Jamie's social worker).

Some young people resented professionals taking on an expert role, assuming they what was best for the young person. The importance of taking time to communicate directly and informally with young people was highlighted by care leavers. Joel, however, found that social workers were often too busy to spend time with him and felt that more resources in terms of more staff would alleviate this situation:

> *Half the time when I went in they were too busy cos they are always getting caseloads... I mean you get like 15, 20 minutes with them... If they have more cases bring more social workers in.*

Jamie's carer echoed this point and stressed that time and patience were essential in supporting young people who often struggled to engage with professionals:

> *They need to be allowed a wee bit more time... That's probably the most valuable thing... I could understand a social worker starting to get a bit fed up with a young person… who just won't engage but sometimes I think maybe a wee bit more patience from the social worker… because these are children that have gone through so much* (Jamie's carer).

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 carer leavers were reluctant to re-engage with 16+ teams as they saw it as a sign of failure. By the time of the second interview, Jamie was no longer in contact with his previous 16+ social worker and explained his difficulty with asking for assistance:

> *I'm not really used to having support… I don't really like to ask for things... for help and stuff… It would probably take me a while to actually give in and say I do need it.*

Similarly, although Joel was struggling with a range of issues including poor housing, mental ill health, difficulties at college and intimidation in his local community, he was not willing to make contact with the 16+ team again:

> *I think they [16+ team] disengaged more than I did.*
>
> Interviewer: Did they say at the end that you could come back and contact them for advice if you wanted to?
> *Yeah.*
>
> Interviewer: But you never did.
> *No... because I don't like them to think that I'm not doing well... It's just to prove a point to myself that I can do it on my own.*

Interestingly, even if Joel did wish to re-engage with the 16+ service, he would not have been eligible as he did not return to college until after his 21st birthday. The current leaving care policy to cease 16+ services at the age of 21 if the young person is not engaged in education, training or employment disadvantaged young people who were struggling to engage in education or training due to mental health needs, intellectual disabilities or parenting responsibilities. Care leavers in these situations felt that 16+ services should allow these young people time to improve their health or adjust to parental roles before engaging in education or training and should have an opportunity to resume contact with 16+ services if they re-commenced education or training courses after the age of 21.

Raising the age at which young people ceased to be supported by social services was also strongly recommended by birth parents and carers who felt that 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:

> *There's a lot of the ones that have left them at the age of 21 and they're in trouble... They've had support since they were put into care... and then they have nothing... They're failing, getting into drugs, thieving, drinking… ruining their lives... There should actually be something there for them* (Alana's parent).
>
> *You wouldn't throw your own child out at 18. Why would you throw a child that is in care who has never had that loving experience at the start of their lives? We are sending very vulnerable young people out into the world. Crazy… Dawn has special needs and she has been thrown out at 18… She has nobody looking after her needs… and maybe because she had been in care she should automatically get one* (Dawn's carer).

In addition, some carers felt they needed more ongoing support from 16+ services after the young person in their care was over 21:

> *A social worker should stay sort of involved occasionally… I know people say 'Well look he's 21 now'… but it's different for children who've been through the care system. They don't have the same confidence or courage… At 21 a person that has been through the care system isn't really 21... They're definitely more immature... No understanding of where money comes from... because everything is provided up until you're 18... When Jamie was 21 it was just like a big bang and I found myself on my own trying to do everything and I had nobody because I couldn't ring the social worker or PA anymore. As well as Jamie being lost, I was lost… I could have been doing with somebody… to tell me what's available for Jamie or what courses he could do. I didn't know what way to turn* (Jamie's carer).

Social workers were also concerned about the withdrawal of services at age 21 or 24 for care leavers in a vulnerable position with very limited formal or informal support in the community:

> *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... 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).
>
> *I understand resources are limited so I'm not saying we remain involved indefinitely but even just for a short period to help them get through that particular time... That cut off once they turn 21 and they are not in education or training is very black and white and we close our involvement and I think there needs to be some flexibility with that... even for a three month period* (Susan's social worker).

Social workers indicated that there may be grounds to argue for the case to be held open for a short period after the cut off stage of the service:

> *Sometimes you do try and plead your case... if there was a situation where a young person was deemed to still require a level of support… It wouldn't just be a case of close the file, we don't care anymore* (Joanne's social worker).

A few care leavers had benefitted from extended support from the 16+ team, particularly if they were presenting with high level needs and were not accessing any other services. For example, Connie, who had poor mental health, was able to have her 16+ support extended by several months beyond her 21st birthday as she was engaged with a police enquiry. Her PA explained this decision:

> *Well there's been periods of significant dips in Connie's mental health and we just wanted somebody around… that Connie could fall back on if she needed after she would age out of our service and because of the different investigations involved. We went up the line and asked could we support her for a bit longer, just in case any of this re-traumatised her and impacted on how settled she is* (Connie's PA).

Sixteen plus teams played an important role as a main referral point to other services who could provide specialist support to meet the range of care leavers' needs. This signposting to other services was important for those ageing out of 16+ services or who had disengaged from 16+ services. However, young people often found it difficult to engage with support from unfamiliar, specialist agencies as they lacked confidence in their ability to engage with new professionals and organisations.

For those who had close relationships with 16+ social workers or PAs, there was often a preference to draw on their emotional and practical support rather than accessing support from other sources. Indeed, emotional support was cited by many care leavers as one of the main valuable resources offered by 16+ social workers. As a consequence, 16+ services often became a one-stop-shop of support for some young people. David, for example, declined support from an autism service, preferring to seek all aspects of support from his PA, with whom he had developed a close relationship. Similarly, Jake, who has Asperger's Syndrome and was estranged from his birth family and not engaged in any form of education, training or employment, lived alone and relied heavily on both his 16+ social worker and PA who contacted him several times per week to offer emotional and practical support. Such care leavers were often anxious about ageing out of 16+ services and felt uncertain about how they will cope independently once the service is 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).

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:

> *In this Trust... the PA carries the case on a normal day to day basis and the case remains against the social worker to respond if it's needed… and then with your hardest group, it's all hands on deck* (Charlie's social worker).

However, at the time of interviews with social workers, there were plans to withdraw social work involvement for those over 18 years and rely more on PA support for these older care leavers.

Young people had varying experiences of services from both 16+ social workers and PAs highlighting the importance of relationship and trust. The following two sub-sections of the report will focus on services from 16+ social workers and PAs.

3.5.1.1 Sixteen+ Social Work Support

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 because they were aged 21years 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 (all from two Trust areas) because they had a child or adult disability social worker who solely led on their case. The other two young people did not have a 16+ social worker because they were over 21 and not in education, training or employment.

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+ and LAC social work services, noting how 16+ social workers treated them more as adults and involved them in plans and decisions affecting their lives. For example, Tony appreciated his social worker's approach to encouraging him to develop independence skills required for adult life:

> *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).

Similarly, social workers indicated that 16+ services had a different approach because the young people were moving into young adult life:

> *16+ have a different approach... We would point out if we don't think that is a good idea but we wouldn't push the issue… because, although we are in a parental role, we are very conscious that we are not their parents. They are sometimes making their own decisions anyway... It's about sort of advising them and guiding them* (Sara's social worker).

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:

> *My social workers would have like seen how much money I was getting... and writing down a list of all the stuff I would need, like groceries, electric and other basic stuff you need. So I wasn't just being fired in there and just having to do it all myself* (Jamie).

> *If I ever need help with anything. If I ever need new clothes you know for a special occasion and I don't have a lot of money. She would help me. And stuff for the house. She helped me out a lot to get my house done up. She's lovely* (Sara).

Care leavers often lacked the level of confidence required to interact with housing and education agencies and were also appreciative of their social worker's help to liaise with other professionals and agencies on their behalf as Joanne explained:

> *She's so quick, on the ball, and she got on the phone to the housing executive and just basically said 'Look when is the keys coming to her?' because I was waiting for a week... and they just kept putting it off... Then I got the keys… I'm not good talking to people so she's sort of like my 'go to' person and then she sorts it out and comes back.*

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'… She went the extra mile, she really did* (Louise).

Similarly, Joanne's former foster carers felt her 16+ social worker made every effort to promote her emotional wellbeing and help her with mental health and appointments:

> *She [16+ social worker] has been exceptional. She has went out of her way… She has been one 110% there… Mental health wasn't going to give her an appointment for ages and she rang them and… fought with them for 20 minutes and they were able to give her an appointment... Nobody else actually took the time to go that extra step and push her into facing what was going on… and she rings Joanne… more often than what any of the rest of them did… and say 'Joanne you've this appointment tomorrow. Don't forget to go to it'… All of those wee things that only take five minutes but she does them and it's a big difference* (Joanne's former foster carer).

Diane echoed these sentiments:

> *It was a lot to do with the social worker… 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.*

Social workers indicated that working in 16+ services required a particular skill set that was quite different to traditional family and child care practice and was more focused on working directly with young people in a flexible manner, often after usual working hours:

> *Anyone working in this profession has come into it because they've wanted to assist young people so they will try as best they can to support and to help the young people… There is a lot of staff out there who are working really incredibly hard and maybe going the extra mile... There might be an occasion that a young person will ring in a crisis and they won't just be left... Staff will work very closely with them they will maybe go with them to the hospital and… stay with them until they are seen and then if they are discharged form hospital they will maybe bring them home, get them some groceries in and all those practical things and sit with them* (Susan's social worker).

Rapport and trust were essential to a successful working relationship between care leavers and social workers. Tony described the importance of familiarity and consistency in developing the type of relationship required for in-depth discussion of personal issues:

> *I find it so much easier to talk to X [social worker] now, because I have known him for years, than it is to maybe talk to somebody that I have only known for one year. Even if I get on well with the person... it is very hard to talk about deep… or have an in-depth conversation when you have hardly met them... Consistency is important* (Tony).

Social workers also emphasised the importance of developing a sound working relationship grounded in trust, particularly when care leavers presented with ongoing emotional needs or challenging behaviours:

> *I've a really good relationship with her... It's a lot about a really consistent approach with Norah... The key is trust and good relationships and consistency in relationships too* (Norah's social worker).
>
> *I would have a very positive relationship with Diane... She was very challenging and she was in and out of trouble constantly.... but she would listen to me, take advice... She once said 'You could say things to me that I'd take somebody else's head off for'. I felt she would have a lot of respect for me. At times I suppose would have treated me a bit like a mother figure to her. We got on well and... even though you would be giving out to her constantly... she would make you smile* (Diane's social worker).

Social workers understood the reasons why some young people were difficult to engage with and had insight into the ongoing impact of past traumas and disrupted personal lives on their current lives:

> *She's very controlling of what information she gives me but that's ok because I know where that comes from... You know your privileged because you have that relationship with them because they have not had it with anyone else and that's what pushes you on and makes you want to continue with the work* (Laura's social worker).
>
> *At the beginning I found her a very difficult young person to engage with, very cold, not communicative... This was an issue that she had probably with meeting new people, not trusting. It took me I'm sure a couple of months in getting her to come out with me to go for a coffee on our own... Now me and her would get on well... so it's just through determination and perseverance really* (Chloe's social worker).

Social workers highlighted the need 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:

> *We have a good relationship, definitely a good working rapport. The most important thing for Jake is establishing trust with me as his social worker and I suppose it did take three months of working with him before that was established... Once we had that level of trust, engaging Jake at his level and addressing the issues which were important to Jake, not what was important to the Trust... that worked well... especially with the Asperger's. It's engaging everything at his level and as much as possible letting him lead his care planning* (Jake's social worker).

> *At the start she absolutely hated me... but the relationship has got good now... She wasn't great at meeting new folk… I just was able to persist with her… It worked... One Easter, I gave her a card and wished her happy Easter. And she said 'Were you thinking about me to buy me a card and all?' and I said 'Yeah'. And from then on in it improved... Those wee small things seem to make a difference... That seemed to really hit the spot with her* (Connie's PA).

For care leavers diagnosed with more severe and complex impairments who were living in specialist hospital 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 and following the young person's lead:

> *Paul got to know me really by me going down observing... I would have spent time with him in his classroom and juice break... But I would have took the lead from those who knew Paul best so as not to upset his routine so that he felt comfortable about accepting me into his environment because that can sometimes be a struggle* (Paul's social worker).

Whilst most young people enjoyed very supportive social work relationships, not all young people spoke positively about their social workers. Susan, who regularly engaged in substance misuse, had viewed social work input into her life as an unwanted interference and failed to share their concerns regarding her vulnerability in the community. However, by the end of the study Susan's view of social workers had changed and she spoke positively about her 16+ social worker who had assisted her to move into a supported placement:

> *I didn't realise it at the time. I just thought everyone was against me all the time… I couldn't wait [to leave care]… I was looked after properly... My social worker helped me… just being there and helping me. Telling me what was going on. Telling me what was best for me… Yeah we had a good relationship… You actually trust somebody* (Susan).

Danny felt his social worker could have given more financial support when he was leaving care. As Danny returned to live with his birth mother he did not receive the leaving care funding he felt he was entitled to:

> *When I left care, they said 'Danny anything you need we can get it for you'. Our fridge started to break and I decided to ask them… And they said 'Oh no no no. Because you went home you don't count for all of this stuff'.*

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 your social worker is doing her job...correctly… Make*

> *sure your social worker gets a really plain clear point of what you want… Be straight, upfront* (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).
>
> *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).
>
> *Resources are a big thing... Any kind of additional supports or extras are nearly all gone now... and the more cases you get, the less staff time you can give to your young people then ultimately they suffer for that... Engagement becomes an issue when you are not available or you can't get out cos you have too much on or you don't have the capacity to visit with added cases you have* (Jake's social worker).
>
> *You're just trying to put out fires constantly… That seems to be the thing with the mental health for me anyway... You spend so much time dealing with hospital admissions, police involvement, writing up your incident reports* (Danny's social worker).

Another key threat to close relationship building was a care management style of working where additional services were introduced to undertake different pieces of work with the young person and the social worker became a coordinator with less time available to spend with young people:

> *The social work model is to care manage and to take more cases and see the young people less and just coordinate the package of other support services but definitely care leavers prefer a consistent relationship and rapport with a core number of people... That's fundamental, good working practice but I suppose with the demands on resources in the Trust you are more being directed now to see your young people less and less and if you can get a bolt on service to do the work that's the way you are directed* (Jake's social worker).

A further challenge to close working relationships was staff turnover. Many young people had experienced multiple changes to their assigned social worker during their time in care and found that 16+ social work staffing remained more consistent. For example, Jamie, who had been in care since the age of five years old, recalled having had a large number of social workers during his time in care but enjoyed a consistent relationship with one 16+ social worker:

> *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 [16+ 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).

Social workers also noted that 16+ services had a high degree of consistency in staff allocated to care leavers:

> *Usually when they are allocated a worker here, that's probably the most consistent that they have had... I've been here five years and have nearly the same caseload so there's a degree of consistency... We do that very well here... and young people get to know other workers in the service well. We do the residential, the social events and activities so they might get to meet other people in the service so it's not always a stranger to them if the case does have to be changed over* (Sara's social worker).

> *They want consistency. They want a worker that knows their background, listens to them and understands them... They don't want to be farmed out to 4 different bolt on services and so that is the big strength in 16+ they have consistency... Someone at 16 saying 'I'll be here. I'll be your social worker for at least 5 years'... and that's that level of trust that you build up that's what takes you through the good times and bad* (Jake's social worker).

However, others had experienced multiple changes to their assigned 16+ 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:

> *It has been a bit more difficult whenever there's been gaps of maybe no worker in place or maybe changes of workers... When new workers are trying to get a handle on a case and then moving on in a couple of months, it's not great* (Simon's social worker).

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, as one social worker who had recently taken on a new case explained:

> *I've worked with Paul for quite a short period actually coming towards his transition... I'm not a 100% sure who was his social worker before that... I think there was a few social workers… a few changes and a new management system... Prior to that I think he might have been without for a wee while... and all those little nuggets of information that the worker had developed over a period of time with that young person, they probably can get lost 'cos it's never going to be 100% recreated for the young person with new workers* (Paul's social worker).

In several cases, the young person's social worker was on longer-term leave and 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. 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. Indeed, staff in 16+ teams had close working relationships and supported each other using a teamwork approach:

> *Good team work is important and if you are going through a rough time. Our team is second to none... if you are in crisis... we wrap round each other... You might work as an individual but you are part of a team and you know they are there when you need them and a young person also get the sense of the team work as well* (Laura's social worker).

3.5.1.2 Personal Advisor (PA) Support

In the case study sample, 18 young people had a PA for at least part of the study. 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 disability social worker leading on their cases in two Trusts where co-working across disability and leaving care services was rare. However, this was not the case in other Trusts where young people could avail of PA support alongside social work support from their disability service:

> *The adult disability workers link in very closely with the PAs in relation to some of our young people moving on to further education... Even in terms of the finance and any support that's available for them* (Simon's social worker).

Social workers from disability services emphasised the importance of disabled care leavers also having access to a PA who could provide targeted support with housing, education and employment. However, in cases where PAs worked alongside adult disability services, there could be some confusion about their various roles:

> *I would put the referral in at age 16 and I've had one young person who did avail of a PA and the PA wasn't really sure what their role was... It was about having that stronger network around the young person for their transition but I think there might have been a view that because... they've got a learning disability and they've got quite a big care package of support around them, the PAs are like 'what are we here for?'... But our young people... should also have people linking in with them about housing... education, getting into employment* (Paul's social worker).

Team leaders explained that flexibility across services was needed so continued involvement with a known social worker could be facilitated for those who struggled to form new relationships and, for others who were well settled, support from a PA could be established:

> *Sometimes there are occasions where they may not have a PA. I've a young person with autism and we don't have a PA allocated... We're trying not to overwhelm this young person… introducing him gradually to the service and the focus at the minute is on the social work relationship... Then there are cases that are PA only… It would be for young people who are quite independent and happy enough… Maybe all they really need is someone to link in with now and again to see how things are going... So they don't feel that they need the social work support... But that's always in agreement with the young person... If their situation deteriorated and it was felt that social work involvement needed to be re-established then that would happen* (Sara's social worker).

However, there was some variance in approach across teams and Trusts in terms of allocation to a PA. 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 until the young person is 21, others indicated that the PA focused more on those who were 18 and over due to the withdrawal of social work support:

> *They should get a PA from 16 but there's a waiting list... Some young people in care don't necessarily need a PA straight away... but we always like to have a PA if they are going to live independently cos they need so much support* (Louise's social worker).

> *All young people 16-21 are meant to have a PA... They don't because there's not enough to go round... It tends to be the under 18s don't have the PAs because they're if they're in residential or foster care there's other members of staff around... It's the 18+ that tend to get a PA* (Dawn's social worker).

> *Technically once they turn 18... they are supposed to get access to a PA... It doesn't always happen... High profile young people who would be quite more complex than the average young person they do tend to be prioritised... and young people with mental health and learning difficulties would be prioritised and they would tend to get a PA* (Susan's social worker).

For others, contact with PAs varied over time, reflecting changing needs and the complexities of the young person's needs. For example, Alana had only seen her PA every couple of months at early stages of the study but had begun to engage with her PA more often as she later commenced a work placement arranged via the employability service linked to the 16+ team. Her PA accompanied her to meetings and health checks required to establish this work placement and was a key contact when any issues emerged on placement.

In some cases, due to staff shortages, young people had been advised that their PA would temporarily not be available to meet with them but they could call into the 16+ service office if needed. Social workers commented on the problem with securing a consistent PA in some cases:

> *Well she had a PA and then the PA was off sick... It takes a long time to recruit so it took a while to get another... Then the second PA went on maternity leave… So there would have been a period where she didn't have one* (Dawn's social worker).

For those who did have access to as PA, their role often involved practical support and advice alongside emotional support. Most young people gave positive accounts of their PAs, as Chloe explained:

> *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).

Chloe's former carer described how her PA and social worker engaged effectively with her network of support:

> *Chloe's PA would be in a lot of contact with her… Chloe's social worker and PA have been very, very good. One of them would see her every week and I see her, you know, most days, we keep in contact. So she does have support* (Chloe's former carer).

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. Jake, a young person with Asperger's syndrome, compared his social worker's approach to that of his PA who dealt with matters in a more efficient and timely fashion:

> *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. Maybe doesn't get round to doing stuff or just can't be arsed. But the PA would do it for you* (Jake).

Similarly, David who was also living alone and estranged from his birth family, relied heavily on his PA for practical and emotional support:

> *My social worker went off on maternity leave and I wasn't assigned anyone else and the PA just did it all... He's my PA though I technically see him as a friend as well... To be honest he does everything... which is supposed to be done... I don't go to anyone else... He is just on the end of the phone regarding anything that comes up... He tells you the way he sees things which is what you need… He is able to tell me when I am doing something completely stupid… If I didn't have him, things wouldn't have turned out the way they have... A relationship is a big thing especially*

> *to me and it is people who I trust and are completely honest and are able to tell me what they think that's what I trust the most... I think we know each other really well.*

Likewise, Joanne also had developed a strong bond with her PA whom she had first met as a member of staff in her former children's home. The informality of their relationship was important for Joanne:

> *I loved having her as my PA. When I was in the kids home, she was an 'as and when' social worker there… She helped me with finances... She was brilliant… 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.*

Interestingly, in both David's and Joanne's cases, their PAs had prior experience of working with young people in residential care. Both PAs had known these care leavers for some time and had benefited from the opportunity to develop long-term working relationships with these young people.

Some care leavers who had strong relationships with PAs did not wish to engage with newly allocated PAs or other agencies or sources of support. For example, by the end of the study however, Joanne was without a PA and was not keen to access a new PA:

> *She left and I'm on a waiting list apparently for a new one. But that was about six months ago… I'm not really bothered.*

Similarly, Louise's social worker commented:

> *She's very attached to the PA... She didn't want to get too close to the new PA out of disloyalty to her* (Louise's social worker)

Such young people were often also reluctant to turn to other specialist professionals for additional support. For example, Connie's severe mental health needs and difficulty in forming new relationships meant that she preferred to rely on her PA for a range of multiple support needs instead of engaging with other specialist professionals:

> *Back in the day I didn't really talk to anybody else... Floating support and all came but I didn't want them... I always had PA... She's good... That's all I wanted when I left care to help me… She takes care of my health and housing... I wouldn't trust nobody but I do trust her.*

Social workers and PAs commented on the role of PAs, emphasising the importance of their relationships with young people from the age of 16 and the practical support they provided for care leavers:

> *The PA is such an important role for the young person... Once the young person is 18… the PA really does come in to their own when the young person leaves care and other professional services disappear at 18. So it's important from 16 that time is used for relationship building… you don't want to get to a stage at 18 where the young person is maybe out independently and there is no relationship with the PA because it will be a very important network for them* (Sara's social worker).

David's PA also highlighted the importance of building close, trust-based relationships with young people including befriending, advising and understanding their impairment related needs:

> *I'm not classed as a professional worker... Your role has to be a befriending role. There is no relationship without somebody seeing you as a friend cos a friend will always challenge you... and also tell you when you are out of line... Sometimes the PA role is how you use yourself... With*

> *Asperger’s it's maybe giving an extra couple of sessions than you would normally plan to allow them to build a bit of trust in you* (David's PA).

Similarly, young people emphasised the importance of informal relationships with 16+ staff, as Tony explained:

> *It’s always good to have a good friendly relationship with your young person because if a young person sees you as a friend rather than a person that you have to go and see then they are going to be a lot more willing and a lot more comfortable talking to you about sensitive subjects… A good relationship is key* (Tony).

The informality of the relationship between PAs and young people also meant that PAs were sometimes following up with young people beyond working hours:

> *You end up giving an awful lot more of your own time… Given mental health issues or drug or alcohol misuse or family circumstances... they can require more time and support and to some degree befriending... You might not be able to move them that far but it’s just somebody that’s not belittling them... That might be as much as keeping the contact with them... A wee text message every now and then. It’s lovely when a wee youngster says 'Thanks for the wee message'* (David's PA).

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:

> *The whole point of the PAs is the PAs aren’t social workers... PAs were always meant to be there as the advocate for the young people even if it was against the Trust. They are not allowed to do that now... I think it was easier when PAs were managed separately... not being part of the system when young people are suspicious of social services involvement* (Jack's social worker).

However, close collaboration between PAs and social workers was also identified as a core foundation for producing better outcomes for care leavers.

> *Me and the PA would have been her main source of support and the two of us had a brilliant working relationship and it had a very positive impact then on the young person. She knew that one of us was always at the other end of the phone... She knew the two of us would communicate with each other... and we would make sure everything the young person needed was done quickly... really recognising whose strengths lay where and who could take on what different roles and responsibilities to help her at where she was at that time* (Belinda's social worker).

PAs and social workers often shared the workload on a case in relation to contact with a young person:

> *If it’s monthly visits the social worker might go one week then two weeks later the PA will go so every two weeks so they are seeing somebody* (Jack's social worker).
>
> *With Jake between myself and his PA he has been seen probably weekly... a dual support... Say I was off on annual leave he would still have the PA and vice versa so he's got a more seamless level of support in here* (Jake's social worker).

Whilst most care leavers had good working relationships with their PA, not every care leaver had such positive experiences. For example, Jack explained that his PA was inflexible with times to visit his home, adopting a procedural approach and failing to invest in their relationship:

> *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).

Interestingly, Jack's PA felt he was difficult to engage with and tended to only respond to the 16+ team when he had a particular support need, although she felt that his pattern of communication could be linked to the effects of his impairment:

> *It got to the stage where he would only contact us when he needed support otherwise it was very difficult to get hold of him... He wants something done now and if you can't do that you are useless to him... but when he has got that out of his system the next day he will be your best friend… I think that's to do with the Asperger's* (Jack's social worker).

Similarly, Laura found it difficult to engage with her PA:

> *I don't like her. I think she is too nosey… She asks too many questions… I never see her, and then when I do she just sits there and questions me… I don't see the use in her.*

The views from some care leavers that PAs were overly-intrusive could reflect their association with social services and close collaboration with social workers. Danny's former carer felt the PA service could be more effective at supporting care leavers if it was independent from 16+ social work services:

> *So many of the young people are resentful of the fact that the PAs are as far as they're concerned still part of the system and they're social workers. So I don't honestly believe they're the ones in the best position to do the job... Young people didn't want a social worker after they were 18 to tell them what to do... They wanted someone they could call their own. But these guys… are not independent. They've still got a conflict of interest* (Danny's former carer).

Whilst there was variation in the allocation of PAs, their role usually ceased for young people aged 21. In a small number of cases, there was some discussion of extending PA support beyond this timeframe:

> *If we think it's to her benefit and she agrees we would probably continue on to be involved with her... because the work placement is lead by the service... I don't think we will be closing any doors* (Alana's social worker).

Indeed, social workers and PAs reflected on challenging cases that had produced positive outcomes for young people and emphasised how professionals working with those young people had been flexible and willing to continue to invest in their relationship well beyond the usual boundaries of their professional duties:

> *One young man who reached 21 came to the end of all our services… He refused to get assessed by adult services... He had a befriender who is still involved with him... so that befriender who's service finished at 21 continued in that relationship... This guy has recognised that this fellow needed that support... It can't happen with us because you end up with your caseload will just expand but some of the befrienders will be specific for these youngsters and they will continue beyond 21 and that is their saving grace* (Laura's social worker).

As some former foster carers played important, often unpaid and unrecognised, 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 as 16+ services closed. However, there were also boundaries to the role, as Charlie's social worker explained:

> *There's a move now to make a wider range of Person Specific PAs and... foster carers could be recognised as Person Specific Personal Advisors... Some foster carers are good at it... but if you're living in a foster placement should that foster carer be your PA? I'm not sure but certainly that idea about the foster carers taking a greater lead role* (Charlie's social worker).

This social worker also felt there may be particular benefits of PSPAs for disabled care leavers who could be supported by someone who already knows them well, however, it would carry additional administrative responsibilities for management:

> *Person specific PAs might be very valuable to people with disabilities because it's somebody they identify themselves they already have a relationship with... It's an administrative pain because one of our PAs here will carry 25 cases. They sit down and do supervision, two hours… she's done for the month but you would have to invite in 25 people to do 25 supervisions for the same every young people if it's PSPAs… It's a big stress but every piece of research is saying get that relationship right* (Charlie's social worker).

SUMMARY

Overall, experiences of 16+ services were favourable with some young people highlighting valued relationships and key supports from social workers and PAs in the 16+ service. Indeed, some young people felt that their social worker or PA had 'gone the extra mile' in supporting their transitions from care and advocating for them in their post-care lives. Care leavers also preferred how this service treated them as adults and had few staff turnovers. However, there were also examples of poorer practice where care leavers felt their rights as adults were not respected and continued involvement with social services was either changeable or overly intrusive.

There was concern for some young people with ongoing needs who were engaged in risk-taking behaviours but who had disengaged from services. Encouraging these young people to avail of mainstream supports in the community or specialist services was emphasised, alongside the possibility of using personalised PAs (PSPAs) to provide more informal individualised support for young people. Given that some young people relied heavily on their 16+ social worker or PA, PSPAs could provide a bridge to more informal and mainstreamed sources of support for care leavers as they move further into their young adult lives.

There was a view that 16+ services focused on younger care leavers or those presenting with highest levels of need or risk with a reduction in services as young people aged over 18, and again when they aged 21. Some young people with mental health and/or intellectual disabilities needed more time to find a secure place to live, negotiate post-care family relationships and learn how to cope independently, before they could engage in education, training or employment. Respondents were, therefore, concerned about the withdrawal of 16+ services for such young people and indicated a need to extend the service to post 21 for some young people who were not yet in education, training or employment.

3.5.2 Disability Services

This section of the report discusses the provision of child and/or adult disability services for care leavers. The challenges with regard to access to these services will be explored in addition to the roles these service providers played in the lives of disabled care leavers.

3.5.2.1 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 or nursing care and a range of family support services. Disabled care leavers could have access to children's disability services until they were 18 when they could transition to adult disability services if they meet their admission criteria.

Some care leavers with borderline impairments, however, struggled 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 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:

> *It’s interesting that a lot of our young people have been statemented in school and gone through the care system and... it hasn’t been picked up beforehand.... when it is a lot easier to access clinical psychologists to do the assessments... Then we’re rushing to get a diagnosis before they’re 19* (Dawn's social worker).

> *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* (Jamie's social worker).

> *We have young people with learning disability and autism coming in and it really baffles me how... we’re only getting the diagnosis that they meet the criteria for adult learning disability services when they’re 18. It’s a common occurrence... So those children should actually have been availing of children’s disability services as well as LAC... How it wasn’t picked up, I do not know* (Norah's social worker).

When disabled care leavers were known to 16+ and disabled children’s services, there was variation across Trusts in terms of which team held lead responsibility. In some cases, children's disability teams took the lead with assistance from a 16+ PA:

> *We hold cases when disabled children are LAC... because people need to have advice from those specialist in disability... We’re experts in it. We do it all the time* (Johnny's social worker).

> *If they’re going to go from child to adult disability services… they get their social work support with children’s disability up to 18 and then adult services from 18+ cos it’s lifelong support. But they are entitled to the 16+… setting up home money, the GEM scheme, the befriending scheme, all of that. They just don’t get a social worker from the 16+ team* (Lorna's social worker).

However, in other cases, the 16+ social worker led on the case with input from children's disability services, when required. For example, Linda had been assessed as having a severe learning disability and had moved on to adult disability services by the end of the study, however, whilst she was aged 16-18, the 16+ social worker led on her case:

> *Children's disability don’t have a statutory responsibility… They mightn’t see the family for six months… So I don’t understand what the protocol is... We’re [16+] the ones who have the responsibility of seeing them… It’s basically left with us... but I’m probably not aware of all the different services or what funding they have* (Linda's social worker).

At times, social workers in 16+ teams were frustrated by the lack of involvement of children's disability services when the child clearly had disability related needs:

> *In terms of learning disability absolutely no links... Children's disability have their link with adult disability but we wouldn't and we wouldn't be able to access any of their supports… and that's really a stone wall* (Jake's social worker).

Likewise, however, social workers in children's disability teams felt they had to undertake all roles for disabled young people in transition with little input from 16+ teams:

> *The disability social worker would be co-ordinating things... The transition is part of that 16+ role... but we do all that and have the other case load as well* (Paul's social worker).

Overall, staff in both 16+ and disability teams felt that it would be helpful if they could work more closely together, even at the level of seeking advice and guidance:

> *I've never really interfaced with the disability team... In my experience... it's rare… It 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 disability* (Imogen's social worker).
>
> *There is very little working with learning disability. It's something I actually do think needs to be developed cos we could really learn a lot from the learning disability services and how they interact and work with their young adults. It would help inform us for whenever we are doing the pathway plan review with a young person to give us more creative ways of how to pass information over to the young person... That needs to happen definitely* (Susan's social worker).
>
> *16+ don't become involved because they are with children's disability but sometimes you are not sure actually what services there are... cos you don't have that link with the 16+ social worker to keep you right... Even if there is a check list to make sure that they are getting everything they are entitled to... like aftercare grants and making sure the aftercare review is held within a certain time frame... and what you should be making a referral for* (Belinda's social worker).

In our case study sample, 10 of the 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. The two young people with intellectual disabilities who did not access children's disability services had mild intellectual disabilities. Social workers described to a range of roles fulfilled by their children's disability team for young people in our case study. In addition to input from a range of health and social care professionals from children's disability services, the children's disability social worker fulfilled a range of duties:

> *My role with him would have been monitoring the placement, organising his LAC review... I would have met with him on a monthly visit minimum and then a co-ordinating role… The go between for the parents and oversee the transition as well* (Paul's social worker).

For some young people, their use of children's disability services was minimal and they had limited relationships with social work staff. For example, Belinda knew her children's disability social worker's name but was unable to offer information about her role, stating: '*I don't see her that often'.* Charlie also had difficulty remembering both the identity of his children's disability social worker and when he last had contact with her:

> *I don't know who she is. I barely see her.*

Some disabled care leavers seemed confused about the role of the various social workers involved in their lives. For example, Linda and her family were unsure of the specific purpose of the three social workers from across children's disability and leaving care services who were currently working with her. Linda had experienced several changes in social workers adding to the confusion as to the roles played by each:

> *It's 16+ at the minute that she's with now. The first one was sick. It was X that was taking her place for a while... Then she's quit altogether... We've had a lot of social workers. I can't even count that many. That's not even an exaggeration. There's just so many different ones* (Linda's sibling).

Other young people were more informed and positive about their involvement with children's disability services. Sam, for example, explained how children's disability services had helped them to understand the effects of his impairment and develop more effective strategies and skills to enhance his social life and independent living skills:

> *They made a difference by helping me through foster care and then they helped me through respite… They came once a month... They helped with my ADHD and with my learning disability. That was very important. I wanted to have a better relationship with people and good friends… When I was in foster care I couldn't read. I couldn't spell or write. But now I'm doing really good… It would have been X [children's disability social worker]… who helped with my cooking, washing, laundry, ironing.*

Sam's former carer echoed these views, adding how this social worker linked Sam into other services:

> *Once he got the diagnosis of the learning disability he was referred to the children's disability team and allocated a social worker and he was very helpful… getting him access to services.*

An important benefit of having involvement from children's disability service was the opportunity to be referred on to a transition service and to adult disability services. Accessing these transition and adult services helped to make a planned move to adult accommodation and provided support from a transition coordinator who worked in collaboration with school staff. For example, as Simon prepared for his move from his GEM foster care placement to supported living, he had support from a transition coordinator from the children's disability service, a PA from 16+ services and a social worker from the adult disability service. These professionals worked together with his school to build a person-centred transition plan based on his views and those of his carer.

In addition, involvement with children's disability services offered access to specialist professionals who could provide further assistance as young people prepared to leave care. For example, Simon's occupational therapist and school worked together on a programme to teach him how to use public transport so he would be able to travel independently when he left care. His carer also appreciated the support from his children's disability social worker who was upfront in her interactions with Simon and understood his needs:

> *X [children's disability social worker] just had a very good relationship with him. She was very up front with him, not afraid to speak her mind… and he was the same then with her. She spent a lot of time with him… doing a lot of the family contacts, so she had a good… idea of what the family was like and what she could expect and how it might affect him* (Simon's carer).

Sam's transition from a specialist foster placement to a supported accommodation for adults with intellectual disabilities was particularly anxiety provoking. He was supported by his children's disability social worker, who sought to minimise his distress by ensuring he understood upcoming changes and had a phased move to his new home, as Sam explained:

> *She [children’s disability social worker] talked about leaving care and going into a new environment, people who help you… And then she told me about… staff here. They’re really good and they would help you a lot… I had a few visits and sometimes I slept over here and gave it a try… I’m here now and… I’m very settled.*

SUMMARY

Disabled care leavers are entitled to support from 16+ services as they age out of care and children's disability services until the age of 18 when they may transition to adult disability services if they meet their admission criteria. However, there was some concern for care leavers with borderline or mild levels of impairment who struggled to access children's disability services.

When disabled care leavers were known to 16+ and children's disability services, there was variation across Trusts in terms of which team held lead responsibility. In some Trusts, children's disability teams led on the case, sometimes with assistance from a 16+ PA. However, staff in children's disability services often found it repetitive to complete the pathway planning documents required for care leavers alongside their own person-centred transition planning processes. In other Trusts, the 16+ social worker led on the case with input from children's disability services, when required. In some of these cases there was limited involvement with children's disability services as lead statutory responsibility sat with the 16+ social worker.

An important benefit of having involvement from children’s disability services was the opportunity to be referred to adult disability services and transition coordinators who worked in collaboration with school staff, although some disabled young people still experienced delays in decisions about post-care accommodation dependent on funding from adult services. In addition, involvement with children’s disability services offered access to specialist professionals who could provide further assistance as young people prepared to leave care including occupational therapy input in relation to independent travel training.

Some disabled care leavers were confused about the role of various social workers involved in their lives especially when they experienced several changes in social work staffing. Other young people were more informed and positive about the involvement of social workers from children’s disability services, particularly in relation to understanding their impairment and learning how to enhance their social and independent living skills. Overall, staff in both 16+ and disability teams felt that it would be helpful if they could work more closely together on care planning and support for disabled care leavers.

3.5.2.2 Adult Disability Services

In our case studies, three of the 10 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.

The remaining seven 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 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:

> *Where the young person has a succinct diagnosis the move over to learning disability team is absolutely beautiful... everything moves so well...* (Linda's social worker).

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:

> *When he turns 18 he's going across to adult disability social work... It should be a smooth transition. His adult learning disability social worker… has already started making referrals to community services... so staff can become immediately involved pretty much when he moves... There's one behaviour support nurse covering children and adults… so that service remains the same person* (Declan's social worker).

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:

> *The psychologist continues on into adult services, which is good... He was doing a lot of work in preparation… what would change and what wouldn't change* (Simon's social worker).

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 like a lot of this just is left to the last minute... We have a number of young people who have had to wait for some time to get actually the support they need from the adult learning disability team.... 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 coming 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)

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 tightly stretched... Some of our young people 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 children's disability 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:

> *Quite a lot of pre-18 diagnosis of disability or moderate disability magically become above the 70 threshold post-18... There is only one that I have had that was below 70 when adult disability reassessed him* (Connie's social worker).
>
> *If we feel that they need to be reassessed then we would make that referral... but it's really difficult sometimes to get that done… When they are still a child essentially so 16 or 17... it's much easier. Once they reach 18 you're obviously working with adults... If we would look at a referral to have them assessed for a learning disability then simply because maybe they don't have a history of it they won't touch it even though we would have serious concerns... Obviously we don't want to be labelling young people but ensuring that they have the supports available to them* (Sam's social worker).

Some social workers highlighted how this re-assessment process was used as a method of gatekeeping access to adult services:

> *Every service has to have a criteria and a cut of point... For children's disability, we're 0-18. For adults they are 18/19 to the grave so they have a larger pool that they have to work for, therefore, their criteria understandably has to be different because… they have to be spread out more* (Declan's social worker).
>
> *More often adult services are saying they want the young person to have a reassessment to make sure they are accepting referrals that do meet the criteria* (Belinda's social worker).

Delays in access to assessment had a significant impact on care leavers who were ageing out of children's services:

> *We can refer directly to adult learning disability services... but it could take maybe 6-8 months for them to make a decision* (Norah's social worker).
>
> *From the point of referral for one young person... his assessment was completed... 14/15 months later and additional information has been requested before adult disability services will take on responsibility for that 18 now 19 year old. So it is slow* (Connie's social worker).
>
> *There is maybe a 3 month waiting list before an appointment date is made available for clinical psychology... If it's a real priority they will try and push that through but it's not always possible and it could still take a few months before there's any support offered* (Belinda's social worker).

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 still be useful for 16+ staff working with the young person:

> *We requested an assessment and it was felt he didn't meet the criteria for adult learning disability services but his scoring was so varied... He had problems within social situations... speak and language, communicating... They said he was very good at understanding information if it was in a picture type form… and his processing skills took quite a long time as well so we were able to get that feedback from the assessment. Even though he wasn't eligible for learning disability services it was good to inform how we could engage with him... give him some time to think through what I am saying and answer... and then whenever we are passing on significant information to him I try to get a picture to go along with it* (Susan's social worker).

It was expected that the 16+ service would meet the needs of disabled care leavers who did not gain access to disability services. 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 don't meet learning disability but there's clearly issues... The need for routine.... the limited skills... the behaviours... the vulnerability... but they're on the cusp and just 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.... The skills you need to work with these guys is completely different... That falls back on you to do that* (Danny's social worker).

> *Adult learning disability is just black and white. If you don't meet the criteria for their service we get no additional supports or advice from them… but some young people clearly need to be involved with a disability team... who is specifically focused on the disability and access to disability supports... and supported living placements that offer more support and monitoring... If we are putting somebody with a learning disability to the housing executive or a hostel they are completely vulnerable to being exploited* ((Jake's social worker).

> *To move onto adult services you have to have a diagnosed severe learning disability. If you had a moderate learning disability and you're highly vulnerable and obviously do need those support services but don't qualify for it... where would that young person be?* (Paul's social worker).

Once accessed, social workers across disability and 16+ teams were aware of the benefits of accessing adult disability services including increased access to ongoing specialist support and a greater range of support options:

> *Simon wasn't sure whether or not he wanted to have a social worker from the adult team... We were trying to explain to him… he has to be known to the adult team to have his application for supported living in... Once they move into adult learning disability services, they still have a lifelong service and support* (Simon's social worker).

However, there were some concerns about the more limited level of contact young people would have with their adult disability social worker. For example, as Simon transferred from child to adult disability services, he commented on low levels of contact with his adult disability social worker:

> *You don't see her much. You only see her if you need to. That's kind of how adults [services] work… It just depends what I need.*

By the end of the study, Rick was no longer being assisted by the 16+ team and, as his GEM placement had ceased, responsibility for his placement had transferred to adult services. However, he had limited contact with his adult disability social worker. Similarly, Sam, a young man who was living in a supported accommodation setting described how he felt dissatisfied with low levels of communication from adult services:

> *It's alright, I would expect more… I was supposed to do clothes shopping last year and it never happened and I was supposed to go on holiday this year but the manager didn't get back to me… I just haven't heard.*

Likewise, Belinda, Declan and Paul had little face-to-face contact with their adult social workers and were unsure of the identity of their social worker. Furthermore, Declan and Belinda's key workers in specialist adult residential disability placements were not aware of the identity of their social workers or the extent of their role. However, Paul's support worker was able to explain his social worker's role:

> *I've only seen her twice in his reviews. So I've never seen them both together... She would deal more with the paperwork side of it… send the reports… Say we're having problems, she'll get in contact with the behavioural team and see what they're doing and try and push it through… and she would give suggestions and ensure that we're supporting him the way we should* (Paul's support worker).

Paul's mother felt the adult disability team worked optimally in response to crisis occurrences, requiring immediate action:

> *She [adult disability social worker] has been great as a signpost. When he had several major melt downs… we literally did not know what to do. I was able to phone her and she was just able to talk me through what you do next. She put us in touch with the behavioural support people… and they have been involved ever since. That has been really helpful... so as a crisis driven thing she has been great* (Paul's mother).

In contrast, Belinda's mother did not know the identity of her daughter's new adult disability social worker, even though she was living in an adult placement. Similarly, although Charlie had been assigned to an adult disability social worker, he struggled to remember who this person was and information regarding their role in his life. He did, however, readily recall the identity of his 16+ social worker.

Due to the reduction in contact with a social worker when disabled young people transitioned to adult disability services, 16+ staff sometimes preferred to have continued involvement:

> *When they are eligible for adult learning disability services and hit 18… 16+ would filter out or might even just stop their involvement... and in some cases that's a good idea but there are some cases... I would actually worry for the child moving to adult disability services cos they don't have the same level of input. They don't necessarily see the social worker the same amount of time* (Susan's social worker).

> *For another girl I had, adult disability really took it over... There was no social worker to be involved from 16+ and I would have continued to see her as a PA... I never hear tell of the adult social worker... adult disability services provide specialist services... but it needs the PA from here with regards the ongoing regular contact* (David's PA).

In a small number of cases, 16+ and adult disability social workers co-worked on cases:

> *When she turned 18 she's been technically co-worked... There's been a social worker in the adult disability team identified cos they fund the adult placement... but they wish to continue co-working the case... until she reaches 19... She has only met her adult disability social worker once... We are the ones supporting mum with… day to day stuff arising from the placement* (Belinda's social worker).

> *There's still a bit of who does what and adult services are sort of asking us to fill out quite a bit of their information... the 80 page person-centred planning document and additional stuff... And then it is them accepting our assessment of what that young person needs as that might be at odds with their services or their agenda... That's where the co-working should really come in* (Paul's social worker).

SUMMARY

In contrast to children's disability services, criteria for access to adult disability services was clearly based on level of impairment and care leavers who had borderline or mild to moderate intellectual disabilities usually did not meet their eligibility criteria. 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 no longer had access to disability services. There was also concern from social workers about delays in securing an assessment of disability for young people ageing out of care.

Social workers indicated that 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 some cases, much effort was 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 alongside ongoing involvement with specialists who knew the young person well. However, 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.

Social workers across disability and 16+ teams were aware of the benefits of adult disability services including access to a greater range of ongoing specialist support options. Young people accessing adult disability services could continue to avail of their PA from the 16+ service, however, adult disability services usually took lead social work responsibility for these young people. There were some concerns, however, about the more limited level of contact young people had with their adult disability social worker compared to the regular contact 16+ social workers maintained with young people.

3.5.2.3 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:

> *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:

> *For a lot of our services you have to have a severe learning disability as well as ASD. It's always been a real problem for me... We would come across people… where the impact of autism far outreaches the impact of any of the other disabilities that we might be dealing with yet policy means that they don't get the same services but… if you brought in autism fully like we should do, the health service would collapse* (Johnny's social worker).

> *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).

Staff in 16+ teams indicated that they needed more training to develop their own knowledge and understanding of ASD rather than learning by experience when they were allocated to a case of a care leaver with ASD or relying on advice from over-stretched autism teams:

> *I have a young person on the autistic spectrum at the minute and I'm just finding my way with that and trying to get some sort of advice on how to work with this young person... It's my first ASD case and... I'm finding it quite difficult… I need more training and more information about his needs... We're very much taking advice from the ASD team until we get to know him better* (Sara's social worker).
>
> *I've only one young person who would be on the spectrum... She really would be somebody that couldn't live independently very easily... but there's no extra services it's just us trying to work our way through it... That's a gap... It's quite scary cos… she's gonna need a lot of work and.... we're not specifically trained so whether we do the right thing is the other thing* (Louise's social worker).

Many social workers and PAs expressed concerns 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:

> *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 you know 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... It's not a learning disability, it's not a mental health issue. It's very hard to get your resources for support on autism* (Rick's social worker).

In some Trusts, in response to this gap in provision, 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. Autism teams for both children and adults set up in Trusts also had a high number of referrals and focused on diagnosis and short-term interventions:

> *There's an ASD team through from children to adults and they're Trust wide… The numbers are huge... There's all the early intervention and diagnostic teams... In terms of social work involvement, they don't hold long-term cases* (Simon's social worker).
>
> *The adult autism service... will do diagnosis in adulthood which is very good... but they only really do the adult diagnosis* (Dawn's social worker).

Social workers recalled cases where young people with autism could not access necessary support and experienced negative outcomes as a result, including a drift into the criminal justice sector and engagement in risky behaviours:

> *I have a young person with... 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... Asperger's isn't counted as a disability... 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 the young offender's centre... This lad needs more... but we had terrible problems getting anything for him...* (Jack's social worker).

> *I had one guy with Asperger's that... just stopped communicating with everybody... He fell in with a really bad crowd and… did years in jail and he just fell right off* (Charlie'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 group care and social settings. As a result, these young people were missing out on key sources of support as professionals focused on their behaviour rather than their ASD related needs:

> *I worked with a young person that had autism up in residential and he was more extreme in terms of behaviour management and he was passed from pillar to post... He was deemed too high of a risk and… there was no specialist place for him to go to... It was quite concerning to me... People were just seeing the behaviour. They weren't seeing what was behind the behaviour and the lack of support available to that young person.... They didn't see what was going on for him, you know, that came secondary really* (Joanne's social worker).

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 sought to access mainstream provision:

> *I have one young person with autism and group living is always very difficult for him... understanding other people's feelings... other young people were treating him differently... and then sort of trying to bully him... so that was difficult for him… He'd always just hit out and use physical violence... in a group setting... It's not something that goes away... People are just very stand-offish because of all the assaults. It's very difficult to get people on board or to get services for him that he should be getting* (Jamie's social worker).

> *Young people coming through our service may have a forensic background often borne out of their autism that has left them frustrated or maybe being put into a children's home with autistic tendencies and an inability to understand those systems has caused them to lash out, not being able to verbalise their frustrations and thoughts... maybe threats to staff… There is a big fear in adult services of taking on the risk that is associated* (Connie's social worker).

There were also concerns about delays in the assessment and diagnosis of ASD with several young people in the study being diagnosed with ASD well into their teenage years or as they prepared to leave care:

> *He needed an updated assessment at 16 and… trying to get an updated assessment was an absolute nightmare* (David's PA).

Imogen was diagnosed at 16 as she was preparing to leave care. She had a troubled experience of residential care finding it difficult to live in group care settings and responding with challenging behaviours which led to involvement with youth justice services. She struggled to accept the diagnosis at this late stage and her parent felt that, if she had been diagnosed earlier, interventions could have been put in place to more effectively meet her needs. Her social worker concurred with this viewpoint:

> *There had been a delay in diagnosis... You would have thought that could have happened as a matter of priority really particularly coming into the care system... for staff and people who are caring for her in terms of having the best ways to help her manage... cos there has been different approaches in terms of her care so that's been difficult… I think at that time her self-harm behaviour was up so I suppose those issues that are presenting on the surface are the ones that are managed first* (Imogen's social worker).

Reflecting Imogen's experience, other young people diagnosed in their late teenage years also found it difficult to accept their ASD diagnosis and, as a result, disengaged from diagnostic assessments and disability services:

> *I had a young person I was trying to get assessed but… he wouldn't do it… They done an IQ test on him first and he didn't go back to do whatever other tests they were going to be doing... He refused and goes 'You know what, I'm 17, I don't want that label'* (Jamie's social worker).
>
> *There's one lad that I work with with Asperger's who just won't engage whatsoever with any service apart from us... He doesn't want to acknowledge the fact you know 'I have Asperger's'* (Danny's social worker).

Many social workers and PAs indicated that children in the care system should be prioritised for diagnostic assessments to ensure care provided adequately met their needs and to facilitate early intervention:

> *All these young people are in the system from a very early age and are not being assessed properly in their early childhood which has huge impacts for their wellbeing in their adult life and this is a fundamental failure of the system... The problem starts from when they come into care when they can actually be diagnosed and a plan or action strategy can be put in place to support them through their childhood and their teenage years... We are running chasing our tails at this stage of their lives when it's too late for most of them... mental health, Asperger's ADHD assessments should have been done and a plan of action should have been in place following these children with a disability right through their years* (Jack's PA).

3.5.2.4 Services for Care Leavers with Borderline Impairments

There was much 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 were identified as having ongoing unmet mental health and disability-related needs and being particularly vulnerable as they left care:

> *Borderline disability is a big thing and so many of our young people fall into that. I would say a large percentage have either a mild learning disability or mental health, you know, particularly vulnerable... It's quite depressing actually... It's best not to think about it* (Louise's social worker).
>
> *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).*

The vulnerability of these care leavers was accentuated by their lack of access to support services as they did not fit the criteria for disability or mental health services and were forced to rely solely on 16+ services:

> *They'll say well 'They're borderline, they don't have a diagnosis… they can't get our services'... It's awful. It happens so many times... And it can be very difficult to get a diagnosis… You don't want the young person labelled any more than they already are... but sometimes it helps if they are to get the services... It can be hard... It falls on us (Jamie's social worker).*

> *A lot of the ones we sit with here will be borderline learning disability... and have moderate to severe issues socially. They will meet the criteria in terms of having had it from childhood and then intellectually they will just miss out in terms of IQ tests for adult services... 80% of their support needs sit within the realms of adult services and support services that we can't access and that is very difficult* (Jake's social worker).

Social workers also expressed concern about the impact of re-assessment to seek entry to adult services on young people with borderline impairments:

> *If you don't meet the criteria, IQ below 70, you don't get the service... I know a care leaver who was assessed just before his 18th birthday to have an IQ of 70 and he didn't meet the criteria because he was one point above it so he didn't get the service which was extremely damaging for that young man who then characterised himself as a 'retard' and stupid because he had almost met the criteria… He wasn't able to access any support in relation to his borderline learning disability… so it was very hard for him* (Tina's social worker).

Whilst 16+ services did their best to meet the needs of these young people, their staff were not trained in specialist knowledge of disability or mental health and could not secure access to specialist services. Young people with borderline impairments also often struggled to maintain engagement in mainstream 16+ services because of their additional unmet support needs which could present as disengagement or challenging behaviours:

> *Even if they do have the diagnosis of autism, there are no services out there... 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).

> *Sometimes what's difficult is... somebody who is 18, who isn't registered disabled but clearly has learning needs… Their placement is breaking down... and the young person is sitting under a duvet or stomping about... presenting with very childlike responses. It makes it difficult because you are dealing with an 18 year old who in the eyes of the law can go to the housing sector, can be placed in the community... but the young person is still looking at it from a very childlike idea* (Sara's social worker).

It was also challenging when young people with borderline impairments did not perceive themselves to be vulnerable and made decisions about their lives that could put them at further risk:

> *We get a lot of young people who say 'I can't wait until I'm 18 and I get rid of you'… but I know they are very vulnerable and not very independent and will need us... We very clearly see a risk that they don't see... You see them making poor decisions... It's very worrying* (Sara's social worker).

Young people with borderline impairments also struggled to secure appropriate post-care accommodation that adequately met their needs:

> *Options are extremely limited... definitely the lack of supported accommodation isn't easy, particularly for those borderline learning disability* (Connie's social worker).

I've one young person whose placement is breaking down and she would be borderline... She's not registered disabled but she does have learning needs, ADHD, foetal alcohol. She's a number of issues that do increase her vulnerability in any sort of accommodation... To put her into one of the larger projects at 18 puts her at risk from other young people who are more street-wise and exposed to a lot more risky behaviours so... I wish I had an accommodation to refer to where there were staff trained to deal with those particular issues (Sara's social worker).

For a lot of our young people who maybe only have a diagnosis for mild learning disability they are not going to meet that criteria for adult services and we have no additional services available to offer them so they are still going to be going down the mainstream route of where we would be referring any young person… but often it's simply not sufficient enough and you find that they begin to struggle and they flounder (Sam's social worker).

SUMMARY

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 ASD were not eligible for disability services unless they had a co-existing intellectual or physical impairment and, thus, relied on 16+ teams to meet the full range of their needs. However, most social workers and PAs acknowledged they lacked knowledge of ASD and services available to meet their needs and needed more training to develop their own knowledge and understanding of how best to meet the needs of care leavers with ASD.

There were also concerns about delays in the assessment and diagnosis of ASD with several young people in the study diagnosed with ASD well into their teenage years or as they prepared to leave care following a history of misunderstood challenging behaviours in group care settings which led to involvement with youth justice. Young people with a late diagnosis of ASD also often struggled to accept their diagnosis and would have benefitted from earlier support and intervention to more effectively meet their needs. Many social workers and PAs indicated that children in the care system should be prioritised for such diagnostic assessments to ensure early identification of ASD and appropriate care to meet their needs.

Autism teams in Trusts had been established for both children and adults with ASD, however, these teams had a high number of referrals and focused on diagnosis and short-term interventions. Due to unmet need, social workers indicated that care leavers with ASD experienced negative outcomes, including a drift into the criminal justice sector and engagement in risky behaviours.

Social workers and carers were particularly concerned about young people with borderline impairments who had ongoing specialist support needs but could not gain entry to adult services as they did not meet the eligibility criteria. In these cases, 16+ social workers were managing high level risks for these young people and struggling to link them to appropriate services.

3.5.3 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 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 young people 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 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.

3.5.3.1 GP Support for Mental Health Needs

In relation to mental health needs, most care leavers described their GPs as medication prescribers and/or the main gateway for referrals to AMHS. For example, Joanne had sought support from her GP when she experienced a deterioration in her mental health:

> *I took really sick so I did. I was really badly depressed and I was self-harming again. So I went back to the doctors, got my meds sorted and now I'm fine again* (Joanne).

However, some care leavers who had moved to new areas were unsure about how to register with their GP. For example, Simon explained that when he felt in a low mood after moving into supported accommodation he realised he needed help to register with a GP in his new area:

> *I didn't have a doctor for a while because I didn't know they need to know your new address and I didn't know how to do it. And I tried to get staff to do it and staff knew how to do it but they were busy* (Simon).

Social workers also highlighted difficulties with registration with a GP when they moved to a new area which restricted referral to other support services:

> *They're not with a doctor because they haven't got a permanent address... One young man made connection with a doctor… but he couldn't register, therefore, she couldn't refer him to support services* (Laura's social worker).

Following a move, some care leavers felt uneasy about contacting a new GP with whom they were unfamiliar, as Jamie explained:

> *I've only went in to register… I haven't actually went in and talked to him... I didn't mind talking to my last doctor because I was going in whenever I had a problem but 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 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 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:

> *I've had loads of counsellors… There's too many… I hate explaining everything over and over... What's the point in talking to a counsellor? She doesn't really care. She is just going to write it down and then go to her nice wee home* (Chloe).

> *For the depression... I was just put on tablets… I did go back to my doctor and tell them I was having a lot of bother from my family and… a lot of stress… I was pretty low at the time… He said 'Do you want to do any more counselling?' And I said 'I have been through so much of the counselling. It didn't even work'* (Dawn).

Others would have liked their GP to refer them to therapeutic mental health services but referrals for additional support had not been made; or sought reviews of their medication but were advised to see their psychiatrist for changes to medication:

> *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... It's the consultant that has to change it and she has to refer me back before she can do that... but it's only every six months you see the consultant... I did ask the doctor to refer me… to CBT. But she didn't refer me* (Joel).

This low level response to Joel's needs was concerning as he lived alone with no contact with any statutory services and was still engaged in self-harming:

> *I do self-harm the odd time… I just deal with it myself… My GP doesn't know… There is no point in talking to them, sure they are useless* (Joel).

It is also important to note that some care leavers lacked a sound understanding of their mental health condition, the purpose or effects of medication and the need to consistently take prescribed medication. For example, Chloe stopped taking her medication for depression:

> *I am on anti-depressants but I haven't taken then in ages. I took them like twice. Two days and then I thought, I am not taking them* (Chloe).

Chloe's former carer also commented on her sporadic use of prescribed medication:

> *If Chloe takes the medication and she's feeling a wee bit better… she stops taking it and then she's back to square one and it's trying to get her to keep taking it* (Chloe's foster carer).

Similarly, Joanne's carer indicated that she did not have a good understanding of her condition and the importance of consistency in taking prescribed medication:

> *You just have to keep reminding her to take them… Nobody actually sat down and explained to Joanne how the tablets work and what they do. She needs to take them regularly for it to build up in her system for them to be effective. Sometimes I think Joanne thinks 'Oh I'll take two tablets tonight and it's going to work. I'm going out tomorrow night, I'm going to have a drink so I'll not take them'. So there was no consistency there for her taking her tablets to build up the usage for them… Nobody ever explained that to her* (Joanne's carer).

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 often frustrated that these referrals had to come from a GP who may not be easily accessible to the young people or may not be familiar with the young person's care background of full history of mental ill health:

> *The referral to adult mental health has to come via the GP so we have to ask the young person to see the GP and the GP may not know the young person or their background. We may have better understanding but adult mental health will not accept the referrals from ourselves at all... They can wait on a GP appointment maybe for a couple of weeks and… sometimes that short window of opportunity has passed and then they wouldn't go to the GP* (Norah's social worker).

The extent to which young people would openly discuss personal issues and mental health needs with GPs was limited in some cases and 16+ social workers found it more difficult to support and advocate on behalf of care leavers if young people did not consent for 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:

> *Multi-disciplinary team work… could be better... We need good communication. We need to be singing of the same hymn sheet to get the best outcomes for that young person... When we have somebody who is at risk and who has spoken honestly to a GP about it and they are aware that there's a 16+ social worker involved, I would expect that information should have been fed back to myself... I do feel very responsible as the field social worker… I do become frustrated with the GP cos, as much as I appreciate confidentiality, we could have a young person who ends their own life and when you look back on it we have to ask ourselves the question, did we do everything in our power? Me as a social worker, the GP, the AMHS, to ensure that we did everything for that young person that we possibly could* (Joanne's social worker).

SUMMARY

Some young people had a limited understanding of their mental illness or the importance of consistently taking prescribed medication. Care leavers who had moved to new areas were unsure how to register with their GP or felt uneasy about consulting a new GP with whom they were unfamiliar. Without registration with a GP, young people had restricted options for referral to other support services.

GPs could refer care leavers to counselling support or specialist mental health care, however, some young people refused such services. Other care leavers were keen to access therapeutic mental health services but found that their GP was more focused on use of medication. A number of care leavers had also experienced delays in having their medication reviewed as GPs recommended a review appointment with their psychiatrist.

Social workers were often frustrated that referrals to AMHS had to come from a GP who may not be easily accessible to the young people or may not be familiar with the young person. Some 16+ social workers felt that, in cases of high risk, GPs could be more open to communicating with them as part of a multi-disciplinary approach to supporting vulnerable care leavers.

3.5.3.2 Child and Adolescent Mental Health Services

CAMHS were available in each Trust to meet the needs of children and young people with mental health needs, including care leavers. CAMHS adopted a tiered service approach ranging from low level, preventive services to specialist in-patient psychiatric care. 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 psychologists from TSS and valued counselling services from community-based organisations as they were independent from the Trust. For example, although Imogen found the approach of one CAMHS psychologist unhelpful, she commented positively on her relationship with another psychologist working with her from TSS with whom she found she could more easily relate. Imogen had also sought counselling services from a community organisation as they were independent from the Trust and the residential home she was hoping to leave:

> *I started the counsellor off my own back… A bit of support to talk about how I'm coping in here without in here knowing… It's a whole lot easier than having to talk to someone who deals with in here… So it's a bit more support* (Imogen).

Several other 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 '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... 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, as Danny's former carer explained:

> *He came with a basket of issues... but the system itself wasn't geared up for him. CAMHS were there to support him, but because he would go in there being antagonistic, they basically said, 'Well there's the door. Go. We can't work with you'* (Danny's former carer).

Despite these experiences of inadequate or unhelpful support provided by CAMHS, negative comments regarding this service were outweighed by reports of more positive encounters. Young people who had spent significant periods of time in children's psychiatric settings recalled invaluable support they received from CAMHS and appreciated their therapeutic approach, patience and consistency:

> *It was scary… 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).

Whilst some young people had positive experiences of in-patient hospital care, there was a limited range of in-patient care for young people in NI, evident from cases where young people moved to specialist care in England and also in social workers' accounts of struggles to secure in-patient care for young people:

> *The severe lack of inpatient treatment for young people with mental illness is worrying… 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* (Lorna's social worker).

> *There are no services here so I was kinda just passed around… Being in the adult ward was horrible… CAMHS had been searching, trying to get me into the CAMHS wards here but there just wasn't the room then they said 'You are just going to have to go to England'... If I hadn't of got that treatment, I wouldn't be where I am now* (Tina).

On Tina's return home after leaving hospital, she found that specialist services were still lacking in NI and waited some time for access to support services:

> *I discharged myself... I just needed to move on... It was difficult like obviously I had gone from a lot of care to not much and the eating disorder service couldn't take me over here there was a waiting list* (Tina).

Several other participants commented on the general lack of mental health services, emphasising the need to address the lack of readily available support and treatment, when required:

> *In NI mental health services are absolutely shocking. There should definitely be more money invested into it to make it bigger… NI does have the highest suicide rate as well and it's really something they should look into* (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* (Dawn's social worker).

> *We've had young people who are in the midst of a therapeutic process and obviously just because they turn 18, you just can't cut that off... Workers have remained involved and see through certain things... if they have a good long term working relationship with the young person... Sometimes those things just need a wee bit of leeway. If someone has a crisis six weeks before they're 18th birthday... we just can't drop them. It is about the young person's needs and trying to do things in the best way possible* (Sara's social worker).

> *We have a very good flexible CAMHS service that would provide services to lots of 18-19 and even 20 year olds. The consultant psychiatrist would see some of our young people well into their later years... Totally technically outside his remit and we would be very, very much for the extension of CAMHS to 21 years of age* (Charlie's social worker).

Many social workers, however, referred to waiting lists and delays for access to CAMHS, particularly for those who had co-existing intellectual disabilities. For example, Johnny had co-existing mental health and intellectual disabilities, however, his social worker struggled to access support for his mental health needs:

> *The waiting list to get into it the psychiatrist was horrific, terrible... I even physically went 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* (Johnny's social worker).

Indeed, social workers indicated that there was a reliance on psychiatric services in the intellectual disability sector to meet the additional mental health needs of care leavers with intellectual disabilities. In these cases, although the therapeutic needs of young people were related to their pre-care or in-care experiences or challenging family dynamics, the service focus was primarily on their intellectual disability:

> *We've loads of cases of dual diagnosis, mental health and learning disability. We [learning disability services] hold those... CAMHS don't get involved in any learning disability cases* (Johnny's social worker).

> *CAMHS won't become involved if the young person has a learning disability so that's where we would then be seeking clinical psychology or psychiatry from learning disability but their services are specialised to learning disability services* (Belinda's social worker).

In contrast, young people with ASD who had mental health needs could access CAMHS.

Social workers also highlighted issues relating to access to CAMHS for those with undiagnosed mental illnesses:

> *Sometimes it's like a tennis ball, back and forward and back and forward and it's very hard. We would have some young people we feel have mental health needs or certainly with repetitive emotional needs, you know, self-harm, vulnerability, at risk and yet... if they don't fit in under a specific box, they may have a personality disorder but they don't have mental health needs, it's not their responsibility and yet we're tied because we can't give any more than what we've got. So there needs to be... something from mental health specifically for adolescents to be better working with ourselves* (Chloe's social worker).

Lack of access to CAMHS for those with undiagnosed mental ill health was problematic given that CAMHS were often reluctant to diagnose mental illness for care leavers which hindered their later access to AMHS:

> *A lot of these youngsters, although they have been in the system, nobody has stopped to diagnose them... 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 wraparound* (Laura's social worker).

> *Most children go into care for neglect or abuse... and are not being diagnosed or assessed for their mental health... They wait til the kids are 14 or 16, they go out and drink and start dabbling into drugs and then we have the whole chaos situation... 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* (Jack's social worker).

These challenges relating to access to CAMHS and AMHS 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:

> *There's a hierarchy including the medical model... We can't actually talk to the psychiatrist and say 'Actually I don't agree with that' because they are seen as god* (Laura's social worker).

For those who could access CAMHS, some social workers indicated that care leavers exited the service too early as their intervention was time limited. Encouraging young people to use CAMHS was also an ongoing role for 16+ staff to avoid young people's disengagement from the service:

> *Trying to get a care leaver who has already been damaged by pre-care experiences and possibly care experiences to open up and talk to somebody is difficult. For someone with learning disability and mental health problems… it's very, very difficult for them to engage in the emotional support and therapeutic intervention* (Connie's social worker).

> *Every other lad I've worked with, the engagement with CAMHS has been minimal. They attend to get their meds increased… but not actually engaging in any sort of meaningful work... in terms of engagement, very very limited* (Danny's social worker).

In addition, social workers indicated that young people often found it difficult to maintain appointments with mental health professionals and engaged better when CAMHS made home or community based visits:

> *The psychologist previously was able to do quite a lot of visits to Sara... but she became more restricted, so it meant Sara had to go to her and there were travel implications and... her training schedule sometimes interfered with appointments* (Sara's social worker).

Social workers highlighted that for some young people with mental health needs, outreach from CAMHS professionals should be more readily available:

> *I have a young person who we hardly see... She's paranoid and anxious… She doesn't leave the house. There's clearly mental health issues so we have done referrals to CAMHS but she won't attend. We can't get CAMHS to do home visits so we're stuck holding the responsibility for her knowing she has mental health but can't get services... The GP can't give medication because it has to come through CAMHS… She's spending her life in a bedroom* (Louise's social worker).

> *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? We're very lucky that we have one worker who will go out to see young people but as a rule, they don't do it... I just can't understand… 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).

Interestingly, in Trusts were CAMHS were physically co-located with 16+ teams, close working relationships had developed across both services:

> *We're very lucky here that the CAMHS team are in house... They share the building with us and they're excellent... We're able like to have a chat with them, just in the kitchen so we're kind of spoilt here. We can get young people seen quite quickly... If you have them on board with the young person, it opens up so many more doors* (Jamie's social worker).
>
> *It's great that we work in the same building as CAMHS... They pop round to us and we pop round to them... CAMHS is brilliant… They're very, very flexible and very efficient... They're on the end of the phone any time you need them... There's an established relationship there... There's never an issue any concern, you just speak to them* (Danny's social worker).

SUMMARY

Social workers highlighted barriers to access to CAMHS, indicating that those with undiagnosed mental illness were often not receiving CAMHS. This was problematic given that CAMHS were often reluctant to diagnose mental illness for care leavers which hindered their later access to AMHS. Many social workers also referred to waiting lists and delays for access to CAMHS, despite presenting needs of care leavers, particularly for those who had co-existing learning disabilities who were often expected to rely on learning disability psychiatric services to have their care-related therapeutic needs met. In contrast, young people with ASD who had mental health needs were directed by 16+ teams to CAMHS. There was also recognition that there was a limited range of in-patient care for young people in NI, evident from cases where young people moved to specialist care in England.

Some young people did not find the CAMHS approach helpful and had a poor working relationship with her CAMHS worker. However, others gave very positive reports of their contact with CAMHS. These young people appreciated their intensive support at times of crisis or hospitalisation, and their patient therapeutic approach to their slow journey to recovery.

Social workers emphasised that CAMHS worked more flexibly than AMHS at the young person's level and pace, often in partnership with 16+ teams. Indeed, this flexibility sometimes extended beyond the age of 18 for engaged care leavers with ongoing needs. In Trusts were CAMHS were physically co-located with 16+ teams, close working relationships had developed across both services.

Some care leavers exited CAMHS too early as their intervention was time limited. Social workers indicated that young people often found it difficult to maintain appointments and engaged better when CAMHS made home or community based visits, which could be more readily offered.

3.5.3.3 Adult Mental Health Services

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 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, 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... so they don't meet the criteria for the 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* (Lorna's social worker).
>
> *The transition from children to adult services is nothing short of abominable in my view... Our 18 years olds who have mental health problems... may feel they don't want the help even though they may require it... 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).
>
> *The difficulty is linking that age group into services and the gap in services... A lot of the times there may not be a particular diagnosis… That's quite frustrating... I have a number where it was constant contact with AMHS… and they were sort of saying "Well that's not mental health, that's behaviour". I'm sort of going 'Well hold on a minute here, you know, your behaviour is affected by your mental health'… I had a young person and it was very, very worrying... She was eventually sectioned but it was a real long hard haul...We shouted from the rooftops basically to be heard, you know, that this young person is ill... We really had to force the issue and she was very, very unwell at the point of admission* (Sara's social worker).

Social workers also recalled cases where care leavers were assessed by AMHS and deemed to not meet their criteria:

> *The majority of young people when they get 18 don't get transferred to the AMHS… when they would be reassessed. Maybe they qualified for CAMHS but not AMHS. I've only had one young person who has actually gone on to AMHS...... I don't actually know what the threshold is for AMHS because obviously a lot of them still have mental health issues* (Louise'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:

> *It's very hard to understand cos looked after children get priority for CAMHS… So that just stops at 18 then it is down to AMHS... and the young person has to go to the GP and the referral has to be made to the team... You are working on a crisis basis, fire fighting... You are almost waiting for something to go wrong before you can act... attempted suicide or come into A&E with an episode* (Jack's PA).

> *Referrals to AMHS can be very difficult because you have to go through a GP. I mean a young person who is well known to the system and has just been discharged from a mental health hospital has to go through their GP... and is expected to sit down and give their life story for the 50th time. We need to be better at all that* (Diane's social worker).

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. Louise transitioned from a children's psychiatric hospital to an adult psychiatric hospital. She reported that, although thoughts of the change were anxiety provoking, she was supported by staff in a gradual process of moving from one setting to the other:

> *It was scary for me... That place [children's psychiatric hospital] was kind of like a wee haven for me… It was not a nice place… but I knew the staff… and I knew what was happening. So the idea of moving for me was terrifying... I just did not want to go… but obviously I had to move. There was no other choice… then kind of settling in and getting to know the staff it did, become… somewhere I could get used to but it was hard* (Louise).

Louise ended up settling well into the adult psychiatric hospital and her social worker commented on how she responded to their approach and ongoing 16+ services:

> *In the adult hospital it is more open... During that time she blossomed, flourished... there wasn't any cutting incidents or serious attempts at ending her life... It's just a combination of breaking away from the adolescent institution, changing medication and maybe a slight change of approach... And then we followed her there… She lost her CAMHS social worker and the medical staff but 16+ were still there* (Louise's social worker).

In contrast, Tina transitioned from a specialist children's hospital to community-based AMHS and described her transition as inadequate, feeling that she was not yet ready to make this change:

> *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?*

Young people also experienced delays in access to AMHS due to lengthy waiting lists which impacted negatively on their ongoing mental ill health. For example, Tina experienced a lapse of mental health services while she waited to be assigned to an AMHS worker and, during this time, her mental health deteriorated. Progress made previously during her time in children's services began to unravel, including, as she points out, advancements associated with an expensive placement and specialist care package:

> *The waiting list to get into it the psychiatrist was terrible… That gap of eight months was horrific… CAMHS didn't want to let me go cos they knew it would be detrimental but the adult couldn't take me on. And it was kind of like 'Well there's nothing really we can do about it'… and it was getting worse again. All the work I had done in hospital was really going back out the window… We'd spent all this money on private hospital that the NHS had to fund… and it was flushed down the drain… It's just ridiculous.*

Social workers also shared their concerns about waiting lists for access to AMHS and lack of recognition for care leavers within the AMHS system:

> *There seems to be too many parts of the system that the focus is keeping people out or 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 some recognition that care leavers have those additional barriers* (Charlie's social worker).

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. However, partnership working between 16+ social workers, young people and AMHS depended on consent from the young person:

> *One of the frustrations with adult mental health is we no longer... phone the GP and say 'We are worried about this' and make the appointment and speak to other professionals... As they reach adulthood we need the young person's consent and a lot of our young people are not willing to give that and so we are powerless to action or support any change* (Sam's social worker).

When care leavers did eventually gain access to AMHS, a 'three strikes and you're out' approach 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 young people and social workers indicated that AMHS was inflexible and did not take into account the needs of care leavers:

> *You might be 18 but you are possibly functioning at a level of 14/15 year old and that affects ability to understand if you don't go to this appointment you are not going to get the supports or the medication... That's going to lead to a deterioration in your mental health and possibly putting yourself at serious risk and at a higher uptake of self-medicating through street drugs as opposed to via a GP* (Connie's social worker).

Joel's experience illustrates this point and highlights some of the issues affecting the difficulties faced by of care leavers in keeping appointments:

> *There was one appointment with AMHS… for half nine in the morning and I wasn't driving and there are 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* (Joel).

Most 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).
>
> *Just trying to get services on board... you're banging your head off a brick wall... It takes that long for a young person to be seen by AMHS and whenever they are seen, it's like three strikes and you're out. That's historical... and very difficult* (Jamie's social worker).
>
> *They are very quickly discharged if they miss two or three appointments, case closed and for a lot of our young people they are not going to re-refer themselves just with what is going on with them… So then that avenue is essentially closed to us* (Sam's social worker).
>
> *CAMHS is very focused on young people. It's very good at the emotional support whereas AMHS is much shorter term. It needs to be based on a specific diagnosis. It needs to be treatable and the young person has to engage and this is what we come up against time and time again, where the young person's not engaging, you've missed two appointments, you're gone and they then start to fall through the cracks* (Charlie's social worker).

> *It can be difficult as I say when we are a young person has maybe missed a mental health appointment by a day… for all sorts of reasons, especially if they're moving around different accommodation… and you ring up 'No sorry go back to the GP' knowing fine to get them back to another appointment is going to take four or five months... They are very clinical in that process and the young people find that very difficult* (Jake's social worker).

Social workers also highlighted how AMHS usually expected young people to attend appointments in their clinic rather than providing home-based appointments which meant some care leavers failed to attend. Only one social worker recalled a case where AMHS had adopted a more flexible approach:

> *It's a lottery. I have a young man… who disengaged from AMHS... and they were very good because usually they say three strikes and you're out... but because of his condition it was recognised that he wouldn't be able to come into an office and they went on outreach to his flat... So adult services are not always black and white… because from the start I said 'He's not going to be engaged with you every time. You are going to have to persist because it is our duty towards that young person'* (Laura'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, creating an unnecessary dependency:

> *If they don't turn up for appointments, they end up discharging them so we end up almost against our better judgement going round, hauling people to mental health appointments to keep them… at 19 and 20 years. So we're going to be closing them at 21 and yet we're creating the dependency… and then when we close them, there's no one to do it... There needs to be a realisation that sometimes they aren't going to turn up because… these people have come from very chaotic lifestyles… They've come from trauma at home and trauma in care and they're still processing that stuff and they're engaging in traumatic activities as care leavers as well so you know, to expect them to you know to turn up to every appointment and then penalise them or throw them off the system and have to go through the whole ream of referrals again is crazy* (Charlie's social worker).

This social worker emphasised that, as there was ongoing corporate parenting responsibility for care leavers, there should be a presumption of their vulnerability to mental health issues for young people who have left care and a more flexible approach up to mental health services up to the age of 25:

> *It's about the fact that care leavers aren't recognised. There is no presumption of vulnerability... Care leavers who have a disability or mental health difficulties have X+Y number of barriers so it's additional barriers on top of the great number of barriers that's already there for being a care leaver. So they are a marginalised group within a marginalised group... They do require that additional focus... Sometimes it's not just enough to offer services. You need to make those services more responsive, particularly when they turn 18... It's just not enough to say well they were offered an appointment... It's more than just offering the services but actively encouraging or facilitating the client to access or use those services, to be flexible to make sure you deliver that therapy or that change... I understand it's in a world with limited resources but I definitely think there is a need for an extension of CAMHS to 21 but if not, the provision of AMHS to care leavers* (Charlie's social worker).

Some social workers also felt that the stigma associated with AMHS influenced young people's willingness to engage:

> *For some young people, there’s a stigma attached to AMHS and they don’t want to go to their GP because… 'They’re going to section me'... and there’s quite a lot of work even getting them to attend and talk openly about it... So you’re then stuck with a lot of risk, a lot of responsibility* (Tony's social worker).

In addition to waiting to receive services for an extensive period of time, young people were often dissatisfied with adult services they eventually accessed. For example, Tina was unhappy with AMHS:

> *I just think mental health services are horrific. I think it’s terrible the way they treat people. My psychiatrist was particularly unhelpful cos she knew me in the adult ward [as a young person]. And then when I went to adult services and was an adult she still treated me like I was 14. I was on a lot of medication that I probably shouldn’t have been on so it wasn’t very nice.*

Most young people who transitioned from CAMHS to AMHS described a stark difference in the service approach:

> *When it came to the adult service… it just felt different… colder* (Norah).

> *CAMHS is far easier to talk to… more relaxed. They are far nicer... 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 walk about the room, 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).

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 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 so there’s not much talking done 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… It’s basically about what medication they can give you to try and help you until your next session… They really don’t seem to care* (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 who could readily liaise with each other with the young person at the centre of care planning:

> *CAMHS prescribe medication and counselling and all… With AMHS it’s just medication based. If you want to talk then they put you onto a psychologist. I think it was just easier to get it all dealt with in the one than having to go here, there and everywhere… They should have all the support networks in the one building. They should have psychiatrists more aware of a psychological point of view because a psychiatrist is just prescribing you medication based on what you’re telling them and they don’t really listen or try and figure out if medication is the best way… or is it counselling that they need… I think there should be a specially trained psychiatrist for people that are leaving child programmes… trained in that particular age group* (Diane).

Moreover, mental health professionals should be given training into the needs of care leavers and there should be alternative routes to support for those who are discharged from AMHS due to difficulties with non-attendance at appointments:

> *Some people with mental health needs tend to run away from it… There's some people that really find it difficult to go to these appointments… I know you can only keep appointments so long and three chances is fair enough but if they're not going for that appointment they should be thinking we can offer them something less full-on… Less intense, counselling in the community, somebody going out and having a cup of tea with them* (Diane).

Jamie felt that more work is needed in reaching out to young people on an emotional level and facilitating an environment conducive to them speaking to trusted professionals about their mental health:

> *I don't think they offer you enough if you've mental health problems... I think they should just help them out a bit, go see them more regularly and talk to them about how they're actually feeling rather than how are you doing in this home... Whenever I was first diagnosed, they knew I had depression but they still never came out to me and ask me how I actually generally was feeling. Even if somebody came out to you and said 'How are you feeling today?'… it would kind of lighten your day a bit* (Jamie).

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).

> *One of my things is being nervous to talk to people about my problems… even with counsellors until I actually got to know them. But when I was moving from counselling to counselling, you're like, I have already said all my life story and now I have to tell another stranger… You have done it so many times and the counselling hasn't worked* (Dawn).

Social workers also noted gaps in the provision of counselling services for young people who transitioned into adult services:

> *Counselling support is extremely hard to get access to due to a high demand. Some of them raise their criteria so you need to be actively suicidal before they offer support. Also young people need to travel into Belfast and a lot of our young people are not motivated to travel anywhere for anything and support needs to come to them sometimes* (Tina's social worker).

Social workers also noted the stark change in service culture for young people transitioning from CAMHS to AMHS:

> *Adolescent services really run and walk alongside until it gets to the point where the young person is then ready to engage... There's too much of a difference in that crossover because there's less of that in adult services... They find that really hard to deal with... It's just a massive change in approach and then young people are left really to their own devices… It really all depends on the GP as to how good they are at recognising and referring* (Imogen's social worker).

> *Adult mental health team is very different by its nature... So although it's potentially lifelong, it's more crisis driven… It mightn't always fulfil their needs* (Louise's social worker).

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. The lack of proactive efforts from AMHS to engage with care leavers was most worrying for those who were ageing out of 16+ services:

> *AMHS have to take responsibility because we're not going to be about forever... AMHS will not follow up with them. For instance if I was to meet a young person here and they didn't turn up, I would be following it up with a phone call and maybe knocking on their door to see where they're at. Adult services will not do that. If they don't turn up for three appointments, that's it. They're discharged from the service for non-attendance. So that is a huge challenge... Their needs would go amiss* (Norah's social worker).
>
> *Mental health services could be seeing a junior doctor or a SHO once every two months and that is the involvement that's being offered… For some, it's what's the point of it?* (Tony's social worker).
>
> *If there is quite an acute presentation… or they present to A&E they will be assessed and the follow-up to that is quite good... The difficulty is if… they aren't assessed as having a plan or being at risk but there is obviously still that mental health need there, there is a gap because they are not going to refer them on elsewhere and there is an expectation that they link in with their GP which typically a lot of our young people won't do* (Sam's social worker).

Most young people struggled to adapt to new regimes in AMHS and others disengaged. Norah clearly communicated how she found this change:

> *With the CAMHS worker it was completely different… She done her job better… There was understanding of the things and she listened and she spoke back. She wasn't like a robot sitting firing questions at you...She talked about things outside of life. She talked about herself... She just made me feel comfortable, that it just wasn't all about me. She made it very easy for me to talk to her… I just got on with her so well... But with the AMHS girl it was like questions she was asking and wrote down on a page... And then whenever you spoke your feelings she would be silent and she would stare at you and you would be like, am I being judged right now? I did not feel comfortable whatsoever… I stopped talking. I just kind of shut down… It was really, really awkward and then there could be these like long silences… I went there twice and would never go back... I didn't really feel like it was a comfortable counselling session... I would go back with CAMHS… if it was possible, but I wouldn't go there [AMHS].*

Joel also struggled to develop a working relationship with his designated psychiatric nurse and purposefully missed appointments as he found her approach intrusive and judgemental:

> *I don't really like her… She's just very nosey… She came in here and she was accusing me of smoking grass... I don't even smoke grass… I don't even smoke…. I keep missing appointments.*

Disengagement from AMHS was a common reaction from young people who found the service culture clinical and lacking in therapeutic support for care leavers. For example, Tina felt the medical approach from CAMHS was well balanced with an important therapeutic element to her care. Conversely, Tina was unhappy with restricted access to therapeutic support whilst she was receiving psychiatric services from AMHS which only focused on medication:

> *I didn't agree with what she [psychiatrist] was doing... She just seemed to want to hand out tablets... They were trying to diagnose me with bipolar recently but they actually decided it was the combination of the two medications that were mimicking the effects of bipolar and they said I never should have been on that combination.*

Her social worker also reflected on Tina's frustration with lack of access to counselling services:

> *Tina herself feels that she needs a talking therapy and counselling but... because she had a psychiatrist she didn't get a counsellor but Tina is saying she is not getting that support from the psychiatrist.*

By the time of the second interview, Tina was not engaged with AMHS due to non-attendance at appointments and she did not avail of any further mental health services for the remainder of the study. Like many care leavers who had been referred to AMHS, her case was closed after several missed appointments, regardless of the reason for non-attendance. Her decision not to request a re-referral was influenced by the focus of this service on medication compared with emotional support she had received from CAMHS:

> *I missed one appointment because it was their fault. And then I missed another appointment because I wasn't well and they just stroked me off the list… They weren't really providing any emotional support. It was just medication. My medication is alright… So I don't think it can really offer me anymore* (Tina).

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. Others depended on informal emotional support from former carers or resorted to self-medicating. However, as David explained, these contacts were not always the best sources of support as they did not have specialist knowledge of mental health disorders or treatments:

> *It's a bit of a difficult one because… my PA is not necessarily the best person to be sort of supporting me through this because… he doesn't know really very much about my disorder.*

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 risk:

> *Norah was reaching that level of concern that her life was in danger… but following her 18th birthday there was no real service there. The adult mental health hospital had a... Monday to Friday inpatient service... and then on a Friday, you were asked to leave and you were re-integrated back into the community... That wasn't any good because weekends were always our worry for her... For young people who are really struggling with their level of drug misuse... there is no local service that will cater for that... at a stage where they would have needed more support* (Norah's social worker).

> *The big worry, risk and challenge is a young person being discharged into the care of a PA who may not have mental health experience... but the medics are discharging these vulnerable young people who hours before had been expressing 'This life isn't worth living'… We are feeling solely responsible for them to the extent that we feel so very vulnerable and the emotional impact of that in terms of staff stress is profound* (Connie's social worker).

Having sole responsibility for the welfare of young people with deteriorating mental illness and at risk of suicide was a challenging experience for 16+ social workers who were deeply concerned about some young people on their caseloads. Indeed, social workers recalled examples of cases where young people known to them had completed suicide and reflected on the impact on 16+ staff:

> *That's the bit I don't like about my job, you are running with huge risks with youngsters with mental health problems... They are high risk takers... We were involved in a case of a young man who unfortunately did die after he was 21… I've gone through all that support we gave that young person. We couldn't have guided him anywhere else but... it's knowing that you are possibly the only person that makes contact with that young person and that they run the risk of taking their own lives* (Diane's social worker).

> *We've had a number of suicides in our team with our over 18 population... The last two were both known to adult mental health services.... It's very difficult for staff to deal with suicide... We run with very high risks I think in the 16+ world and we risk manage frequently a lot of our young people* (Lorna's social worker).

A further gap in provision for care leavers who had transitioned to adult services was the lack of services 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:

> *We have had situations where this lad is sitting with his arms sliced wide open absolutely out of his head on drugs and alcohol... Casualty stitch him up and send him home again. I tried four times to get that lad into mental health and they would never take him in because it was drug and alcohol related... Yes he is taking alcohol because something has happened to this lad in the past and nobody is doing that previous work with him. If we can get him the counselling and support to get those issues out then we might actually get past the alcohol and the drug use and the self-harm* (Jack's PA).

> *Dual diagnosis is a very difficult issue. You can't really work out what's the drugs and what's the mental health issues but she's deteriorated rapidly... She's in this merry-go-round of being deemed a voluntary patient discharging herself and getting involved in drink and drugs... Every part of the system is failing for her and what is needed is a place of safety for her but her personality disorder is not recognised in mental health law* (Charlie's social worker).

Indeed, 16+ social workers had close working relationships with community addictions teams and identified substance misuse as a very common feature of the lives of care leavers:

> *Substance misuse is a massive problem... A lot of their mental health is drug induced and mental health services are not willing to work with them because they say once they are off the drugs the mental health stabilises and they are simply referring them on to addiction services… I think the difficulty is when they reach 18... they have maybe been hospitalised, discharged and back to where they are living and you've maybe only heard a week or two after that's happened and then any opportunity there would have been to address the issue is gone because of they have reverted back to their behaviours again* (Sam's social worker).

Social workers also felt that there was a professional hierarchy within AMHS with medical professionals dominating assessments and decisions and minimal sharing of information from AMHS to 16+ social workers who were most familiar with the needs of care leavers:

> *There is a bit if a hierarchy with the mental health service... Sometimes trying to get information from consultants can be incredibly difficult… Social services will go to their meetings but the consultants won't necessarily go to the social services meetings... Maybe they are concerned*

> *about confidentiality but if they are happy enough to ask for us to share all our information with them then equally they should be willing to share information with social services* (Susan's social worker).
>
> *Sharing of information is a tricky and thorny issue... We had concerns about one young person and… certainly I was giving an update to their psychiatrist or SHO before their appointments but I would never have got anything in return… Equally there's been other psychiatrists who would have no difficulty contacting me in regards to a young person... So I do work very well with them at times* (Tony's social worker).

Social workers in 16+ teams often attended review meetings in AMHS for young people on their caseloads. However, many social workers highlighted that closer co-working across 16+ teams and AMHS is required:

> *I went to get in touch with them, they were to ring back, didn't ring back, contacted them again... This is a period of weeks and I wouldn't have known that she was not attending mental health, had it not been that she had given me permission to speak to the GP who advised me. So you're left very much in the dark and that's why it is fundamental that the multi-disciplinary work becomes paramount really… There is no point in everybody trying to work in isolation with one young person. We all have a common goal, we want the best for this young person… and the best way to do that is that everybody sits round a table, gives their opinion... We're all singing of the same hymn sheet… but it's not happening* (Joanne's social worker).
>
> *The bottom line is we all need to know about the roles and responsibilities of the other workers... For those mental health difficulties, we would have risk strategy meetings… at that, it should be clearly decided who's doing what and in what capacity* (Tony's social worker).

Working in partnership could offer support for AMHS who were less experienced at working with younger adults who have left care and, vice versa, could facilitate access to specialist mental health advice for 16+ teams.

SUMMARY

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 four had recent suicide attempts but were not engaged with AMHS. Social workers expressed much concern for young people who did not have access to AMHS as they did not have a diagnosed mental health disorder and care leavers who dipped in and out of mental health services only availing of short-term care before being discharged.

Seven females were accessing AMHS with all but one having experienced a recent suicide attempt and admission to adolescent psychiatric hospital in relation to their mental illness. None of these seven young people had co-existing disabilities. These care leavers had a range of mental illnesses including diagnoses of personality disorder, bi-polar diagnosis, eating disorder and depression.

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 experienced delays in access to AMHS due to lengthy waiting lists which impacted on their mental 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. However, partnership working between 16+ social workers and AMHS was limited.

If young people missed three clinical appointments with AMHS they were usually discharged and a new referral was required. Such inflexibility did not take into account the needs of care leavers who often missed appointments due to change of address, the effects of their mental health or a current crisis. Some social workers felt that the stigma associated with AMHS influenced young people's willingness to engage in addition to the shift in the culture of services from CAMHS to AMHS from a flexible, therapeutic approach to a more rigid, clinical service culture. Social workers felt there should be a presumption of their vulnerability to mental health issues for young people who have left care and a more flexible approach up to mental health services up to the age of 25.

Young people were often dissatisfied with AMHS, particularly their focus on medication review and clinical diagnosis rather than therapeutic intervention. Young people also noted the reduced time available with AMHS professionals. As a result, some young people disengaged, including those with ongoing mental health needs at risk of self-harm or suicide. Due to disengagement from AMHS, some care leavers developed their own strategies for coping with mental health difficulties including a reliance on 16+ services or former carers for support with mental health needs or self-medicating through substance misuse. Indeed, there was a gap in provision for care leavers with substance misuse issues in addition to mental health needs as AMHS often refused services for these young people.

Social workers in 16+ teams were concerned about holding high level risks for young people who depending on them for support with mental health needs instead of accessing specialist 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. Many social workers highlighted that closer co-working across 16+ teams and AMHS is required.

3.5.4 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 family-based care placements as carers struggled to cope with anti-social or criminal behaviour. For example, Norah's kinship carer threatened to end her placement if she continued to engage in criminal activity linked to substance misuse.

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).

In addition, some young people were actively engaged in support to reduce offending and benefited from a flexible approach from youth justice services, as Imogen's social worker explained:

> *The youth justice worker is very good and they're very flexible with her... They have to work very hard with her… It's certainly been positive in the sense that it's opened up doors into services… She's worked really well with youth justice... and she has had a real sense of achievement from it* (Imogen's social worker).

However, leniency from the police or youth justice sector due to disability was also noted as not being in the best interests of the young person. One carer discussed how the police were disinclined to interview a care leaver due to his intellectual disability but indicated that a police caution would have been beneficial as it would have given him a sense of the seriousness of his behaviour:

> *The police should have come round and explained that this allegation has been made and what you did is wrong. He never had that experience... That would have really give him a really strong message… I didn't want him to have any sort of criminal record but… he just needed the police to come out and caution him... and social services said 'No. We're not gonna do that. His learning disability mitigates against that' but to me that's that was a cop out* (Sam's carer).

For those who were in prison, social workers also shared concerns about how well their disability or mental health related needs were being met within the prison system:

> *We struggle with our young people who go into the prison system who have mental health difficulties... Trying to get across to prison staff these young people are very vulnerable and... that they've got access to their medication* (Lorna's social worker).

Some social workers indicated that those with mental health needs were over-represented in the prison system and had drifted into criminal activity due to unmet mental health needs. One social worker recalled a case where a young person had developed a dependency on secure care in the young offenders' centre which led him to engage in ongoing criminal behaviour:

> *The number of people with mental health problems in jail... because of that cycle, you know, in psychiatric hospital, then out, back in again... The mental health system isn't providing for them and they end up in there. There is one lad who literally just wants to be in the young offenders' centre and they'll say "What are you going to do when you get out?" "Oh I'm going to go to smash the window. See you at five o'clock" and he does... He's back in at five and he lives there because of the structure… It's secure… Now of course when he gets to 21, it won't be the young offender's centre. It will be the adult prison and it's a whole different kettle of fish* (Charlie's social worker).

SUMMARY

A third of the case study sample had a history of involvement with youth justice services at some point. Offences were mainly related to anti-social and/or drug-taking behaviour although a few had committed more serious offences. Most offences were committed while the young people were in care, especially for those in children's residential homes. Supportive programmes were available to young people to assist them in reducing their offending behaviours and a number of young people availed of such programmes and found them helpful. Support for young people to understand the severity and consequences of criminal behaviour was highlighted. In addition, social workers indicated a need for better understanding of disability and mental health in the criminal justice system and as young people at risk are discharged back into the community.

3.5.5 Voluntary Sector Services

Care leavers gained support for their accommodation, education, training and employment from 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, Autism Initiatives, NEXUS); and charities that provided services for the leaving and in-care population (such as, VOYPIC, Barnardos, Action for Children, Include Youth, Belfast Central Mission, 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, 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, as Lorna explained:

> *I quite enjoyed VOYPIC. We done all sorts with VOYPIC… They took us out on day trips to a few places… I quite liked the ones from VOYPIC.*

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, as Louise explained:

> *Their support is brilliant and… along with getting friends and mentors and advocates and stuff, they offer so many opportunities as regard building your CV.*

Social workers also highlighted the important range of services provided by VOYPIC for many of the care leavers they worked with including mentoring and advocacy:

> *VOYPIC is excellent... They would also provide a very good independent information and advocacy for young people... working with us and trying to understand the young person's needs... We would have some young people who get involved in VOYPIC's participation programmes… and VOYPIC would also organise specific groups around maybe independence prep* (Charlie's social worker).

Social workers highlighted the benefits of ongoing floating support and accommodation provided for care leavers from MACS, BCM and Barnardo's. Young people and carers also commented on the benefits of intensive support provided by such agencies:

> *They were absolutely fantastic... I was the sort of person, you tell me what to do, I am going to do the opposite. They did play a big part in helping me change my life from immature teenager to a slightly more responsible adult* (Tony).

> *If you get a letter or something and you didn't understand it… They are a really good support… they would always be there for you* (Charlie).

Some care leavers also completed work focused on drug 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.

Other voluntary organisations, such as Include Youth and the Prince's Trust, provided employability programmes (discussed earlier in section 3.4.2) aimed at increasing young people's self-esteem, confidence and core skills for employment**.**

Several young people had contact with disability-related voluntary organisations such as Praxis care, Autism Initiatives, Mencap, Autism NI, Orchardville, NOW 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. For example, Imogen, who had been recently diagnosed with autism, was enjoying support from a disability organisation:

> *We do drawing or something… It's relaxing really… like a kind of therapy thing. Something fun where you can meet people of your own kind. They all have the same problem you have basically* (Imogen).

Social workers were also very positive about the social opportunities offered by disability organisations, the continuity of their services and programmes aimed at developing young people's skills for employment:

> *I have found them to be an extremely helpful resource. They've carried on counselling and haven't stopped at 18… They offer quite a lot of clubs at night and... get the older young people into volunteering themselves which promotes socialisation as well as a social life* (Rick's social worker).
>
> *They are brilliant... they do little tasters in work placement… and it's fantastic* (Johnny's social worker).

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. Some young people sought out counselling from these services as they were independent from the Trust. 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. Some care leavers also accessed support from mainstream voluntary services in relation to financial difficulties, including the Citizen's Advice Bureau, St Vincent de Paul and Christians Against Poverty.

Several young people, however, 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. In addition, social workers expressed concern about the lack of voluntary sector services in more rural areas due to their centralisation in city areas:

> *We are a rural Trust so our young people wouldn't be able to access the services that a care leaver in Belfast would be… Just logistically to ask the young person from here with Asperger's and low self-esteem to get on a train and go to Belfast they are not that keen. It would be hard enough to get them to engage in their own area... If you were in Belfast or Derry you would be able to access more voluntary supports. We are very very limited that way* (Jake's social worker).

Social workers also acknowledged that some care leavers preferred not to have contact with care leaver organisations because they wanted to distance themselves from the stigma of associated with care experience:

> *There's two types of young people in care. Those that acknowledge and accept that they're in care and those that don't see themselves as a young person in care and would keep their care leaver identity very much in their pocket and would not in a million years think of engaging with VOYPIC... There's others that would have very good involvement, work well with VOYPIC long after we're finished and will help those younger than them who may have experienced something similar* (Tony's social worker).

Similarly, some care leavers were reluctant to avail of disability or mental health related voluntary or community sector organisations due to the perceived stigma associated with disability and mental health.

SUMMARY

Young people availed of a range of support from voluntary sector organisations across the sectors of leaving care, disability and mental health. These organisations provided assistance with training, personal development, employment skills and counselling. Some care leavers also lived in supported accommodation offered by voluntary organisations with intensive support that enabled them to develop skills for moving on to independent living. Young people also benefited from social opportunities and mentoring roles where they could use their experience and skills to support other care leavers. For some young people, availing of mainstream support was important as they preferred to disassociate from stigma related to being in care or having a disability or mental health need. For others, using specialised services was helpful as it gave them an opportunity for shared experience and a safe environment to engage with peers. 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.

3.5.6 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:

> *The better outcomes are invariably when all the professionals involved have worked closely to provide a robust and comprehensive care package and all the agencies attend meetings and contribute and work not in a rushed manner... It's timely and it's relevant* (Sam's social worker).
>
> *We have other cases of 16/17 year olds on the autistic spectrum who are involved with mental health services, disability, criminal justice system, youth justice agency, ourselves, voluntary accommodation providers and there is a co-working that's cohesive and, whilst the complexities are so multi-faceted, the co-working that's involved is exceptional* (Connie's social worker).

However, these examples were rare and depended sometimes on relationships between individual professionals:

> *It would vary between individuals cases definitely... It maybe varies between different social workers as well and maybe the relationships they have developed with certain people as to how well they work together* (Susan's social worker).

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* (Simon's social worker).
>
> *The disability teams have their own plans in place but they are not put together. They work separately… There is no integration... We are not told about them... That could really be improved* (Jack's social worker).

> *Different professionals all have their own agenda and I think that needs to be stripped back and just it's about the young person what needs to be done, by who* (Paul's social worker).

Without access to specialist support, 16+ teams felt they were often supporting care leavers with a wide range of needs with other services not taking responsibility for the additional needs of care leavers with mental health or intellectual disabilities:

> *It is always a battle ground who takes lead responsibility... between learning disability and mental health... and that would bounce back and forward* (Nora's social worker).
>
> *The system as a whole seems to be geared at making entry difficult or making a sustained service difficult* (Charlie's social worker).

There was also concern about a reliance on 16+ teams to solely meet the full range of care leavers' needs as, if alternative support was not in place when they closed cases at 21, young people could be in a very vulnerable position:

> *We generally close young people when they reach the age of 21 and we try and meet the need the best we can and link them in with appropriate services if we can but outside of that we will close them and a lot of young people then find that they become more isolated without support* (Sam's social worker).

Social workers in 16+ teams, 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:

> *Systems at that interface definitely could be improved... As a statutory service we need to match up those systems of referral and involvement. Clarity of roles as well.... We would have rarely ever had adult mental health social worker involvement, other than in-patient admissions. That is rarely followed up with CPN support in the community. It would be a big gap in my experience and quite often then we are as 16+ trying to fight for the young person to get mental health support... I would also say there is very little co working between children's disability and 16+... We need additionality of support... It is just something that is just neglectful of the young people and their needs* (Connie's social worker).

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 or commitment from other services was frustrating. Many social workers indicated that all statutory services needed to have a better understanding of the circumstances of care leavers with mental health and/or intellectual disabilities to respond appropriately to their needs and ensure the fulfilment of corporate parenting duties was prioritised:

> *We had a young person leaving and the autism team was meant to be involved. They came to his last review having not seen him for 18 months prior to that. Now that's not acceptable. If we didn't go and see a young person for 18 months you would be hauled over the coals… They are not doing what they need to be doing... I think there needs to be a priority for some of these young ones who suddenly go from support they have at under 18 to losing it all* (Jack's social worker).
>
> *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).

Indeed, legal knowledge of the entitlement of care leavers was often used by 16+ teams to leverage support from other agencies:

> *Sometimes my staff will come to me and say I phoned such and such and I can't get them to do this... It's just knowing who and how... It's about establishing those links and developing those relationships… It's also then about sometimes needing to be quite assertive and knowing your rights and knowing the rights of the young people... You need to know the law... educating outside agencies... on the world of 16+ kids* (Lorna's social worker).

Overall, there was a need for clearer pathways for care leavers, particularly those with borderline disabilities or lower levels of impairment who did not meet the threshold for adult services and often fell between service gaps:

> *It is terrifying to think of what lies ahead for those two young boys with learning disability who were assessed as not meeting adult services criteria. They're 18 at the minute with a specialist foster carer... but they're only going to be known to us up to the age of 21. The GEM payments will stop so that foster carer is going to be expected to take on other placements. So where does these two young boys go?* (Nora's social worker).

> *Obviously if you just don't meet the criteria it is a black and white decision... Yes, you have moderate severe learning difficulties and complex needs... You are still sitting with high support needs and you would still probably need someone to coordinate your care plan and your package of care for life but... it is a clinical decision that there is no come back on that whatsoever* (Jake's social worker).

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, particularly from child to adult services:

> *The interface between adult disability and adult mental health services definitely needs a more seamless, smoother transition... that black and white interface* (Connie's social worker).

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:

> *Transition policies from child to adult disability services don't mention 16+ services... That whole interaction between how disability carry the case and we provide the PA isn't mentioned in it* (Charlie's social worker).

> *The Leaving Care Act and the Children's Order gives a little bit to a child with a disability but it doesn't really unpick the issues. So maybe teasing that out more… the real issues and how could things be improved and looking at the 16+ team as well... We all have a lot of knowledge in the transition process but I think what we need to get right is a template of how to do it... that everyone will agree on… and we all go on training in that with everyone singing from the same hymn sheet… and the goal posts aren't changed depending on circumstances and individuals* (Paul's social worker).

Indeed, with further investment and collaborative efforts, the role of transition co-ordinators situated in children's disability teams who work with disabled young people in transition from school (age 14-25) could be a useful additional transition support for 16+ teams working with disabled care leavers, as one transition co-ordinator explained:

> *My role really is trying to get pathways for the young people and get decisions, linking in with various other agencies... Look at the young person's wishes in it all... and trying to co-ordinate all the information… and then try and plan ahead where we go with it... It's not just a matter of maybe referring to adult team... There's 16+, supported living, forensic services, psychology, psychiatry, OT, Physio, speech and language... and it's trying to see who needs to be involved when and that you're not overwhelming the people with a load of different bodies all sitting round a meeting, but that you've the right people there at the right time.*

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 16+ teams supporting care leavers with a wide range of needs. Social workers in 16+ teams felt there was a need to highlight the Corporate Parenting responsibilities of all statutory teams with regard to meeting the additional needs of care leavers with mental health or intellectual disabilities. Increased understanding of their unique circumstances and needs among staff in adult services was emphasised which would allow for a more flexible response particularly for care leavers with mental health or intellectual disabilities who do not meet the threshold for adult services. Social workers in 16+ teams also indicated that increased knowledge of the legal rights of care leavers across sectors would also be beneficial.

The main barriers to multi-disciplinary working were resource constraints and separate policies which created service gaps. However, closer collaboration offers the opportunity for more effective use of existing resources and a shared knowledge and skill base. Shared skills in creative, person-centred approaches to transition planning were a good example of the cross fertilisation of practice across children's disability and 16+ teams. Such examples of mutual learning were rare and could become a more common feature of practice with more integrated working transition planning practice grounded in a clear integrated transition policy applied to child and adult disability and mental health services and 16+ services.

Overall, there was a need for clearer pathways from child to adult support services for care leavers, particularly those with borderline disabilities or lower level mental health needs who do not meet the threshold for adult services and often fell between service gaps. Equally, there was also a need for clear pathways onwards from 16+ teams, particularly when cases closed at 21 and for those perceived to have ongoing needs but no access to alternative supports.

3.5.7 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 supporting care leavers with mental health or intellectual disabilities. The two main teams leading on support for these care leavers from the age of 16 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 and issues affecting the lives of care leavers, such as, substance misuse. Some 16+ social workers had accessed training on mental health issues but not all. The extent of disability training for 16+ social workers was even more limited:

> *I haven't accessed any disability or mental health related training... We wouldn't really have the opportunity… A lot of training through the Trust is to do with child protection training. It's not really specifically geared towards care leavers* (Norah's social worker).

> *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... Autism awareness training, when it's advertised, gets filled ten times over* (Lorna's social worker).

> *I haven't had any training around working with people with learning disabilities in social work... Just in university... I wouldn't feel confident and it'd be totally outdated... about their needs and their disabilities in general. I think it's important if you have those clients. I don't have any training on mental health issues either* (Linda's social worker).

> *I don't think in my time in 16+ I have accessed any disability training... but learning disability is something that comes up… So it would be useful to have more training in… how learning disabilities impact on people and what you can access for someone then. 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).

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 independent research to add to their knowledge but had limited access to formal training:

> *I'd be interested in training on autism... Surely you've a general idea and information on autism but I feel I need more specific training on that and also from the child's point of view, from the carers'/parents' point of view* (Chloe's social worker).

> *There's a lot of courses at drugs training and self-harm or mental health... but there's a lack of autism training and we're starting to experience it more and more with young people coming through the care system now who have autism... so we all need it* (Dawn's social worker).

> *When I get a case where there is a particular disability I just do a bit of research myself but I'm not aware of any specific legislation... or training… We're seeing more and more ASD and Asperger's… so I have sought that out myself... just a bit of online research* (Imogen's social worker).

> *We would work a lot of young people would have ADHD, Asperger's and autism and none of us are trained in working with them... I have yet to get onto training for Asperger's… because you do have to work with people in a certain way and if you don't know that and I still don't. I'm learning a bit so I'd love to get training on Asperger's and we have tried... They don't come up very often and anytime they do we haven't been able to get on* (Louise's social worker).

In a few cases, 16+ social workers reflected on how young people with autism did not have their needs well met in mainstream residential child care due to the limited autism related knowledge of staff:

> *I'm thinking of a young guy who had Asperger's and he went into residential and he was treated so inappropriately because they didn't have trained staff... They only think in straight lines and*

> *can only think one thing at once, you have to have that understanding when you are working with them and you cannot complicate things. He kicked off because his food wasn't right and he had gone to his room because that is what he had been told to do but a member of staff followed him, with other youngsters... but with youngsters with Asperger's you wait... This kid threw something at a member of staff and he got criminalised for it because it was the lack of understanding* (Lindsay's social worker).

The lack of training on working with care leavers with autism was concerning to 16+ social workers who felt they were learning about autism from care leavers themselves in the absence of formal training:

> *I had five young people with Asperger's and it was a learning curve for me cos I have never had training in that… 16+ workers have no training on disability issues… and actually I was learning from the young people* (Jack's social worker).

Reflecting the issues relating to multi-disciplinary 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 across sectors to enhance their understanding of each other's roles and responsibilities in relation to meeting the needs of care leavers with mental health and/or intellectual disabilities:

> *The interface between children and adult mental health, I do think there's a kind of information deficit on both sides you know... understanding the remit of each team... how it would lead to better more enhanced working relationships* (Tony's social worker).

> *There is definitely a need for disability teams to have better training about general LAC stuff and we need to have better ideas of what the disability requirements are and maybe joint training on those cases would be helpful* (Charlie's social worker).

Such collaborative training could also help to develop and consolidate ideas on how to integrate services and utilise resources more effectively across sectors:

> *We don't necessarily know what resources there are out there that a mental health or learning disability team may have more awareness of... If there are other teams co-working there might be a bit more access to resources* (Tina's social worker).

Whilst these findings indicate areas where further training should be offered to staff in various teams, social workers also highlighted that time was often a barrier to their participation in training. 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:

> *It's more about the time that a social worker has to go on them... Sometimes you're on the course and a young person is in court and you just have to go to court* (Jamie's social worker).

> *The last couple of training courses I have actually had to cancel two of them because of work commitments... Just everyone is stretched if you take two days out to go on training* (Jake's social worker).

SUMMARY

Staff in 16+ or children's disability teams were often leading on the initial transition support for care leavers. General training relevant to the remit of social workers in both teams was available, however, 16+ social workers struggled to gain access to disability training and children's disability social workers had limited training on care leaver issues. A major gap in training identified by 16+ social workers and PAs was courses on working with care leavers with autism. It was indicated that joint cross-sector training on roles and responsibilities related to care leavers would help to develop knowledge of care leaver issues across child and adult teams and to clarify the role of each team and how best to work together to produce the best possible outcomes for care leavers. It was also important to note that crises in the lives of care leavers were often unpredictable and the demands of case related work in the context of limited staffing in 16+ teams could impact on the availability of social workers to attend training.

4.0 DISCUSSION AND RECCOMMENDATIONS

The findings from the case studies reflect the unique and complex experiences of care leavers with mental health and/or intellectual disabilities, and highlight the importance of both generic and specialist services to meet their specific needs. The case studies provide examples of practice approaches that work well but also key areas where policies and services need further improvement to more adequately meet the needs of these care leavers.

4.1 WHAT WORKS WELL?

There were many examples in care leaver accounts of approaches to practice that worked well, providing meaningful support to young people and helping them to transition to adult life and reach their full potential.

Staff who worked in 16+ teams who were co-located with mental health or disability services had closer working relationships. These were able to engage in informal consultations with specialist colleagues for advice on alternative approaches or additional sources of support. These informal working relationships also led to better formal multi-disciplinary working as teams knew each other well and understood each other's roles and respected their specialist areas of knowledge.

Whilst improvements to pathway planning processes were recommended, generally care leavers over 18 played an active role in decisions about their post-care lives. For young people with severe impairments, participation could be more restricted, however, there was evidence of some 16+ social workers seeking alternative methods of engaging these care leavers in decisions and care plans. For example, adopting 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.

Young people who were leaving longer-term foster care or kinship care placements often had more opportunity to avail of 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 played significant roles in continuing 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 support their recovery. In such cases, it could be possible for former carers to become Person Specific PAs, although these roles needs to be carefully agreed with care leavers with intellectual disabilities who were sometimes keen to reduce ongoing involvement of former carers as it often felt like they were being over-protected. In addition, intensive supported accommodation and supported lodging schemes whereby they were accommodated by carers to live independently in their home worked very well but a limited range of these were available across NI.

Finally, some care leavers described relationships 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 professionals understood the challenges these young people faced and demonstrated much patience, commitment and genuine care for them. There were numerous examples of 16+ social workers and PAs working closely with young people at their pace, 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 which assisted their work including, housing agencies and education providers.

Young people and professionals repeatedly emphasised that working with care leavers demands such a flexible approach that often does not fit well with rigid service structures or procedures. Indeed, some professionals 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 for young people returning to education just beyond the age allowed for financial support; and CAMHS continuing to provide care for a young person who had turned 18 due to an ongoing crisis or an unfinished therapeutic programme.

4.2 WHAT NEEDS TO BE IMPROVED?

The case study findings also indicate clear areas where policies and services need improvement to more effectively meet the needs of care leavers with mental health and/or intellectual disabilities. Corporate parenting responsibilities for a full range of service providers is emphasised, alongside a focus on relationship-based practice and collaboration across service sectors. In addition, the findings highlight the need for a wider focus on shifting discriminatory societal attitudes towards care leavers, disability and mental health.

4.2.1 Early Intervention and In-care Experiences

The findings of the study emphasise the importance of pre-care and in-care experiences and the impact these have on young people transitioning from care. There is a clear need to conduct assessments of the health and disability related needs of children as they come into the care system. Earlier diagnosis and identification of need would provide an opportunity for timely specialist support and intervention and better decisions about the type of care placement that would most effectively meet their needs. It is important that those caring for young people with mental health and/or intellectual disabilities have access to training and support to ensure the care environment and approach effectively meets their needs, particularly for those placed in mainstream residential care placements. In preparation for leaving care, young people also need opportunities for early re-assessment of health and disability related needs rather than waiting until they are close to 18 years old and are unsure about their potential access to adult services.

Whilst in care, some young people with mental health and/or intellectual disabilities experienced much placement disruption which had a detrimental impact on opportunities for permanence, birth family contact and consistent schooling. Efforts should be made to reduce this level of disruption for care leavers mental health and/or intellectual disabilities through greater understanding of the reasons for their placement breakdown and school change and targeted care planning to promote permanence.

Finally, given the experience of care leavers with mental health and/or intellectual disabilities who are parents, the findings highlight the importance of including disabled young people in accessible and disability aware educational programmes about sexual and personal relationships and effective parenting during their time in care.

Recommendations:

1. 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 where staff have specialist training on disability and mental health issues. 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.
2. Disabled young people should be included in educational programmes about sexual and personal relationships and effective parenting during their time in care, ensuring such programmes are accessible and disability aware.
3. Efforts should be made to reduce placement disruption for care leavers mental health and/or intellectual disabilities through greater understanding of the reasons for their placement breakdown and targeted care planning to promote permanence.

4.2.2 Generic Leaving Care Services

The findings from the case studies indicate areas for improvement in 16+ services that would benefit any care leaver but would be particularly helpful for those with mental health and/or intellectual disabilities. For example, young people, social workers and PAs emphasised the need to revise pathway planning documentation to make it less patronising and more appropriate for young adults. Enhancing pathway planning approaches also offers an opportunity to develop more creative, person-centred methods for engaging with care leavers with mental health and/or intellectual disabilities and linking more effectively with schools and disability services to avoid crisis driven, abrupt transitions to adult care placements.

Reflecting the general experiences of care leavers, most young people experienced financial hardship. In addition, some care leavers feared losing the limited income they received from housing or unemployment benefits by engaging in further education or full-time work. 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 as they transition from care including greater use of direct payments and self-directed packages of support.

At 18, care leavers often wanted to live independently but later regretted hasty departures from care without having support in place. These young people often felt socially isolated and struggled to cope with living on their own but were not able to return to former care arrangements. Professionals could do more to encourage young people to consider slower transitions from care, where possible. Peer mentoring from other young people who have aged out of care and have experience of disability/mental health issues may help to inform young people about the realities of life after care and the challenges ahead.

Young people leaving residential care were particularly disadvantaged by the requirement to leave children's homes when they were 18 compared with those who were able to have a more phased transition from foster care or who were able to remain in foster care under the GEM scheme. These young people had more limited informal sources of support and often struggled to cope with the demands of living independently due to their prior reliance on staff to meet their practical needs. Young people leaving residential care need earlier opportunities to learn and practise skills for independent living whilst they are still in care.

There is great concern among social workers that older disabled care leavers have unmet needs as they exit 16+ services and require extended care leaver support. Under current policy, care leavers who are not in education, employment or training and 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 are not in a position to engage in education, employment or training by the age of 21 for a range of reasons including mental ill health, parenting responsibilities or housing crises.

Staff in 16+ teams also expressed much concern for care leavers with borderline or mild to moderate levels of intellectual disability. Raising the age at which these young people cease to be supported by social services was strongly recommended by all respondents as they were considered to be particularly vulnerable to poor outcomes in all areas of life well into their twenties and should be supported for longer than is currently available.

Recommendations:

4. Pathway planning approaches should be revised to ensure they are more responsive to the ongoing challenges in care leavers' lives and utilise more creative, person-centred ways of engaging care leavers with mental health and/or intellectual disabilities, including use of technology. There should also be stronger links with schools and disability/mental health services to avoid duplication of transition plans or crisis driven transitions.
5. An audit 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, including greater use of direct payments and self-directed packages of support.
6. Professionals could do more to encourage young people to consider slower transitions from care, where appropriate, including use of peer mentoring from care experienced young people who also have experience of disability/mental health issues.
7. Young people leaving residential care should have access to more stepped approaches to moving on from care at 18 with access to more intensive support during their time in care and on leaving care to enable them to develop skills for independent living.
8. Care leavers with mental health and/or intellectual disabilities require extended supports as they experience further change and transition well into their twenties. Further access to aftercare or disability services is particularly important for those with borderline or mild to moderate levels of impairment who are particularly vulnerable in the community without access to support services post 21.
9. Care leavers with mental health and/or intellectual disabilities whose 16+ cases close at 21 because they are not in education, employment or training should be carefully reviewed and the needs of these young people assessed to identify if ongoing support from 16+ teams or alternative providers is required.

4.2.3 Pathways from Care and to Specialist Services

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. In addition, there is a need for greater consistency in the role of the GP in terms of referrals to mental health services and use of prescribed medication. It is also important that professionals in AMHS have a sound understanding of the specific needs of young people who have left care and offer a greater range of non-clinical, therapeutic community-based support for care leavers.

The study found a lack of clarity about pathways from child to adult services across the domains of 16+, disability and mental health services. There should be clearer, regionally agreed pathways to specialist services to ensure needs and entitlements are fully met through child to adult services. Staff in 16+ teams should also have access to specialist mental health and disability services for information, advice and assessment, if required.

There are particular sub-groups of care leavers who are falling between service gaps including care leavers with: ASD, borderline levels of intellectual disability and those with mental ill health who are engaged in substance misuse. There is a need to develop services tailored to meet their needs or to widen the remit of existing disability and mental health services to be more inclusive of young people presenting with these needs. There are also geographical variations in the provision of services for care leavers across the province with those in more rural areas being disadvantaged when services are centralised in urban areas.

The study also found a lack of suitable supported housing or adult residential placements for care leavers with mental health and/or intellectual disabilities. Supported accommodation worked well for young people, particularly those providing more intensive support, however, these were often short-term placements with a view to moving into independent living with limited availability. In addition, a lack of in-patient psychiatric care for young people is reported by young people and social workers.

The findings of the case studies 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 could have a greater understanding of disability and mental health issues and disability/mental health organisations could build on their awareness of care leaver issues.

Recommendations:

10. CAMHS could be extended to 21 or 25 for care leavers who require ongoing therapeutic intervention from trusted mental health professionals.
11. Clear regionally agreed pathways from child to adult service provision for care leavers across 16+, disability and mental health services are required.
12. Eligibility criteria for access to specialist mental health or disability services should be based on the assessed needs of care leavers with mental health and/or intellectual disabilities rather than a strict adherence to severity of impairment. Staff in 16+ teams should also have clear pathways of communication with specialist mental health and disability services so they can access information, advice and assessment without delay, if required.
13. There are service gaps for care leavers with: ASD, borderline levels of intellectual disability and those with mental ill health who are engaged in substance misuse. Services should be developed to meet the needs of these young people or existing disability and mental health services should be extended to include these young people within their remit.
14. The availability of specialist in-patient care and longer stay supported accommodation options for care leavers with mental health and/or intellectual disabilities across the region should be reviewed to identify gaps in provision and areas for service development.

4.2.4 Corporate Parenting and Collaboration

As young people with mental health and/or intellectual disabilities leave care, they engage with a range of public agencies with responsibility for education, employment and learning, housing, public health, social security, leisure, youth justice and policing. However, the extent to which these providers understand the particular experiences and needs of care leavers with mental health and/or intellectual disabilities is variable. There is a clear message in the findings of this study that care leavers with mental health and/or intellectual disabilities need to be recognised by all public agencies (both mainstream and specialist) as young people for whom they have ongoing responsibilities. This requires orientation and training for staff at all levels within the organisation. It also requires assessment of the service needs of these care leavers and action to ensure that these young people know about and can access relevant services in an appropriate and timely fashion.

There is a tendency for services to work in silos with a narrow focus on their particular specialism, for example, mental health or intellectual disability. Such categorisation of services is helpful in terms of managing budgets and caseloads, however, it is restrictive for those with co-existing impairments who need access to more than one specialist service or professional. For example, a care leaver with mental health and intellectual disabilities who is known to the disability service should not be excluded from access to specialist mental health services that may more effectively meet their mental health needs at the time of leaving care.

In addition, there is a need for more sharing of knowledge and expertise across specialisms to facilitate more creative ways of working across services. For example, staff in 16+ teams are very keen to develop their knowledge of disability and skills for communicating directly with care leavers with intellectual disabilities. However, they have very limited access to such training or opportunity to liaise with specialists in disability or mental health services who could advise and support them. Likewise, some professionals in child or adult disability teams had limited knowledge of care leaver experiences or entitlements to support services. Within Trusts, professionals should be working across service boundaries to fulfil corporate parenting responsibilities for care leavers with mental health and/or intellectual disabilities. Lead agencies need to take responsibility for engaging with partner agencies to establish and maintain strategic and operational collaborative working practices based on pooled resources, co-located staff and integrated transition services. Indeed, the Children's Services Co-operation Act NI (2015) provides the opportunity and obligation for collaborative assessments of need and integrated services which would be of much benefit to care leavers with mental health and/or intellectual disabilities.

Recommendations:

15. A clear, regional transition policy for care leavers with mental health and/or intellectual disabilities setting out unambiguous roles and responsibilities is required to ensure fulfilment of Corporate Parenting requirements and the duty to co-operate under the Children's Services Co-operation Act (NI) 2015.
16. Joint training and knowledge sharing events bringing together professionals working with care leavers across 16+, mental health and disability teams is required to develop understanding of roles and responsibilities and to facilitate collaboration. Care leavers with mental health and/or intellectual disabilities should be involved in the delivery of such training initiatives.
17. Integrated, multi-disciplinary transition policies and services are required to more effectively meet the needs of care leavers with mental health and/or intellectual disabilities.

4.2.5 Relationship Based Practice

Young people and social workers indicated that relationship-based practice is the cornerstone of effective support for care leavers with mental health and/or intellectual disabilities. When care leavers observed the efforts of professionals to engage in their lives and care for their wellbeing, they found it easier to engage with services and valued the close relationship with their worker. Care leavers also negotiated a range of family dynamics and identity issues on leaving care. When professionals knew care leavers well, young people could share these personal challenges and access support to develop positive self-identities and manage these personal relationships.

Young people and staff in 16+ teams emphasised the importance of understanding how care leavers have difficulty trusting new people and how previous experiences of loss or trauma affect their adult relationships and place them at risk of social isolation. However, effective practitioners were also strengths-based and focused on the capacity of care leavers to learn how to develop and maintain relationships and succeed in their young adult lives. These positive aspirations were particularly important for care leavers with mental health and/or intellectual disabilities for whom professionals often had low expectations for their futures. Drawing on a sound working relationship, professionals could help these care leavers to build their self-confidence, to access support and to realise their full potential and reach their personal goals.

Recommendations:

18. Agencies must prioritise the development of relationship-based practice with care leavers with mental health and/or intellectual disabilities. This requires the retention of staff and structures that allow for stable relationships over time between key front line staff and care leavers.
19. Professionals must seek to, and be supported to, develop their practice methods and skills in providing committed, person centred, relationship based practice that is rights based and takes a strengths perspective.

4.2.6 Social Inclusion

A recurrent theme in the case study data was young people's experience of stigma and discrimination on the grounds of being care experienced, disabled and/or having a mental illness. Some young people experienced overt discrimination, manipulation or abuse. In addition, young people experienced bullying and intimidation in schools/colleges, in their homes and in their local areas which was not adequately addressed by the police service or relevant housing agencies. Prolonged or repeated experiences of bullying or discriminatory treatment negatively affected the self-esteem of care leavers leading to socially isolated lives and exclusion from education, training or employment due to fears of harassment or abuse.

Discriminatory treatment also negatively affected how care leavers perceived their disability or mental illness, with the risk of internalising negative messages about their sense of self. In some cases, young people who were aware that they were at risk of discrimination or negative public attitudes deliberately concealed their identities. Some care leavers also withdrew from specialist services in order to disassociate from labels as a care leaver, disabled person or person with a mental illness.

These findings indicate a need for professional and public education to raise awareness of the rights of these young people and for more therapeutic services for care leavers who have experienced discrimination or abuse. Greater efforts to facilitate the inclusion of care leavers with mental health and/or intellectual disabilities in their local communities are also needed.

Recommendations:

20. Professional and public education is needed to raise awareness of the right of care leavers with mental health and/or intellectual disabilities and the duties of statutory bodies to protect them from discrimination based on their legal rights. There are public campaigns aiming to challenge negative stereotypes about care leavers which need to broaden their reach to include positive messages about young people with mental health and/or intellectual disabilities.
21. Therapeutic supports should be available to care leavers with mental health and/or intellectual disabilities who have experienced discrimination or abuse to help them develop positive self-identities that counteract negative stereotypes.
22. Networks providing peer support from care experienced young people who also have experience of mental health and/or intellectual disability should be supported and encouraged to make links with other socially excluded young people.
23. Community development approaches that facilitate the inclusion of care leavers with mental health and/or intellectual disabilities in their local communities should be used to build their community connectedness and expand their social networks and access to protective and enriching social relationships.

5.0 Conclusion

The review of research literature for this study showed a notable lack of attention to the experiences of disabled care leavers and limited qualitative research on the experiences of care leavers with mental health. Given this lack of previous research, this report makes an important contribution to our understanding of the needs and experiences of care leavers with mental health and/or intellectual disabilities. The case study approach, incorporating a peer research methodology, provides unique insights 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 case study findings provide examples of best practice including: relationship-based practice, flexible approaches to engaging with care leavers and ongoing support from former foster carers. However, there are clear areas for service improvement to enhance support for care leavers with mental health and/or intellectual disabilities and to ensure full implementation of current legal duties. 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, including those with no clear diagnosis, borderline impairments or ASD. Finally, the case study findings highlight deeper issues of structural and cultural oppression and discrimination towards these care leavers in the community which should be challenged under rights-based law in NI.

In conclusion, the recommendations outlined provide clear direction for the future development of policy and practice. 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 with mental health and/or intellectual disabilities.

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