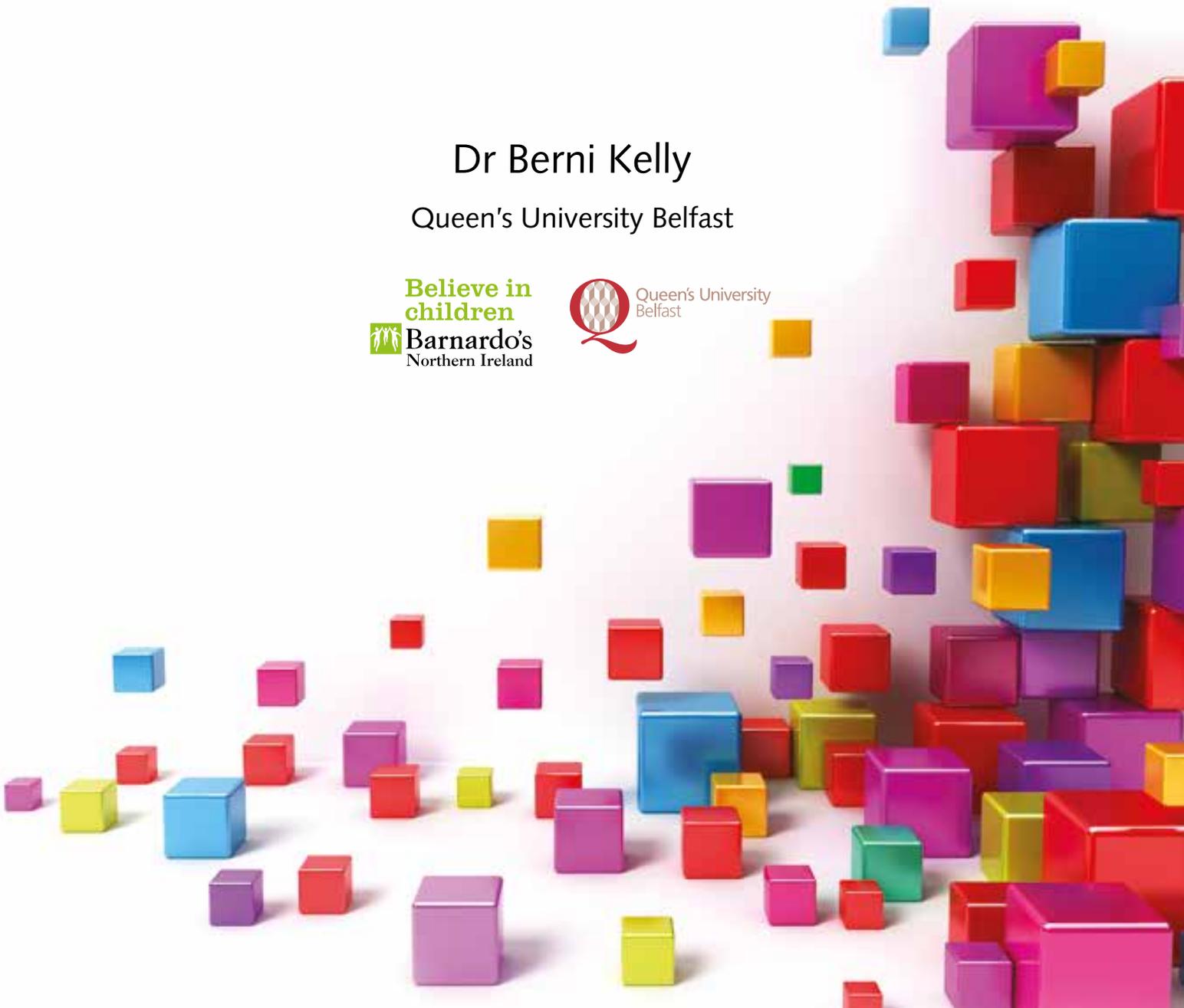


DON'T BOX ME IN!

Disability, Identity
and Transitions to
Young Adult Life

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1. INTRODUCTION

This report presents the findings of a follow-up study of the transitional experiences of ten learning disabled¹ adults who, as children, had participated in a family support study ten years previously (Kelly, 2003, 2005, 2007). To provide a context for the research findings, this section of report provides an outline of the background to the study and a summary of the main changes in policy since the first study. Section two of the report describes the methodological approach and relevant ethical considerations. Section three focuses on the findings of the research organised under five core themes: transitions for young adults and their parents; social exclusion, risk and identities; access to adult services; and the organisational, policy and practice context. Finally, in section four of the report, core priorities for the future development of policy and practice are presented.

1.1 Background to the Study

This report is based on a follow up study of ten young adults who participated in research examining the family support needs of disabled children and their families just over a decade ago. In the first study, these participants were all aged under 18 and were receiving services from their local children's disability social work team. In the current study, they were aged between 20-29 years old and all, except one, were receiving adult disability services. The current study sought to investigate their transitions from child to adult life and explore their young adult life experiences. As this was a follow-up study via adult learning disability teams, the predominant focus was on the social care and social work service context for transitions to adult life although provision from other post-school services was also explored.

Much of the research into disability and young adult life has focused on the process of transition from school into 'adulthood' (Stewart et al., 2001) or adult services in general, without full recognition of the issues relevant to early adult life and the heterogeneous nature of both disability and adulthood (Goodley, 2001). Similarly, the growing body of literature on disability and identity mostly concentrates on physically disabled adults (Watson, 2002; Zitzelsberger, 2005) or disabled children (Davis & Watson, 2001; Kelly, 2005). Less is known about the life experiences of young learning disabled adults, how disability and impairment is incorporated into their identity narratives, or how their experiences of adult services impact on the construction of their identities and life choices. This study sought to examine the interplay of these experiences as part of the process of transition from child to young adult life.

Although current policy and practice places a great emphasis on the importance of a seamless transition to adult life for learning disabled young people, this move from child to adult services is often characterised by a reduction in levels and type of service provision (CSCI, 2007, CDSA, 2012). This is largely a result of traditional impairment-focused adult programmes of care with higher eligibility thresholds (CDSA, 2012; The Post-19 Lobby Group, 2013). Findings from previous research indicate that, although there is much investment in transition, young learning disabled adults can transition into a void or can be forced to rely on limited and inappropriate post-school options

1 The term 'learning disabled' or 'learning disability' is used throughout this report instead of 'intellectual disability' or 'cognitive impairment' to reflect the local practice context and the views of the young adult advisory group.

(Lundy et al., 2012; Morris, 1999; SCIE, 2004). The impact of such changes on their sense of self and their pathways through young adult life has yet to be fully explored. This is the focus of the current study which sought to investigate the impact of services and transition planning on the life experiences of learning disabled young people as they moved into their young adult lives. There has been much development in policy and practice over the past decade with a plethora of new initiatives aimed at improving transition outcomes for disabled young people. This is, therefore, an opportune time to investigate the impact of such policy and service developments on the lives of young learning disabled adults.

1.2 Policy Context

During the decade between the two studies, there has been radical change in the organisational and policy health and social care context in Northern Ireland, including the Review of Public Administration and re-organisation of Health and Social Care Trusts. There has also been major legislation and policy change across the domains of disability, child care and education.

A range of legislation in place at the time of the first study is still relevant to young disabled people's transition to adult life today. For example, duties under the *Chronically Sick and Disabled Persons (NI) Act (1978)*, *Disabled Persons (NI) Act (1989)* and *Code of Practice on the Identification and Assessment of Special Educational Needs (1998)* for education, health and social care sectors to prepare a transition plan for school leavers with special educational needs and provide appropriate advice and support. Likewise, the *Children (NI) Order 1995* is still the main child care statute in Northern Ireland and provides statutory duties to assess the needs of parents of disabled children, to support disabled children and their families and to ascertain the views and wishes of disabled children. Volume five of the Department's regulations and guidance to support the implementation of the Order acknowledged the particular needs of disabled young people in transition to adult life, including duties to plan effectively for the transition to adult life, encourage use of training schemes and provide support in the community to promote independent living.

A range of right-based policies also still influence policy relating to disabled children and/or adults. For example, the principles of the *United Nations Conventions on the Rights of the Child (UNCRC) (1989)* have informed much of the legislation and policy for children in Northern Ireland. However, General Comment 9 (UNCRC, 2006) highlighted that disabled children still experience multiple forms of discrimination and violence, social exclusion and age-inappropriate post-school options (CDSA, 2012; Haydon, 2008; Jones et al., 2007). Indeed, the Northern Ireland Commissioner for Children and Young People has recommended the development of a comprehensive national strategy for the full and effective inclusion of disabled children into society and the provision of a greater range of age-appropriate services for disabled young people as they transition to adult life (NICCY, 2010).

Locally, the *Human Rights Act (1998)*, the *Northern Ireland Act (1998)* and the *Disability Discrimination Act (1995)* are also examples of relevant legislation which promote human rights, equality of opportunity for disabled people and protection from discrimination on the grounds of disability. However, concerns have been raised about



how well the provisions of these laws have been enforced. For example, Haydon (2008: 21) raised concerns about the enforceability of Section 75 of the Northern Ireland Act (1998). Similarly, in a recent evaluation of the Disability Discrimination (NI) Order (2006), McIlwhan et al. (2009) noted the lack of progress in relation to targets for the employment of disabled people. Unfortunately, despite this rights-based legislation, several government and independent research reports continue to provide evidence that many health, education, housing and participation rights are still not fully protected as many disabled people continue to experience social exclusion, poverty, unemployment and discrimination (McMahon and Keenan, 2008; Mencap, 2007; Monteith et al., 2009; OFMDFM, 2009).

A Decade of Disability Policy

Over the past decade there have also been major developments in disability policy. At a global level, the *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)*, ratified in the UK in 2009, addressed the rights of both disabled children and adults. Of particular relevance to transitional experiences, the Convention urges state parties to ensure that disabled people have access to further education, training and employment on an equal basis with others (UNCRPD, 2006). A general theme of the UNCRPD is the right of disabled people to live independently and experience full community inclusion and participation. State parties are also expected to take measures to eliminate discrimination against disabled people in all matters relating to family and relationships. The UK Government's first periodic report on the implementation of the UNCRPD submitted in May 2011 highlighted a range of developments in Northern Ireland including: education transition services; a ministerial sub-group on transition; and a range of supports to enable disabled people to access further education, training and employment. Whilst these initiatives are noteworthy, there is limited reference to evaluation of the effectiveness of these services including uptake across impairment types and long-term outcomes for disabled people. Indeed, the Equality Commission (ECNI, 2012) recently produced a report on the implementation of the UNCRPD in Northern Ireland and identified many shortfalls in provision and policy. In particular, the report highlighted the need for further awareness-raising; participation in political and public life; and data collection and access to information. Multi-level intervention was recommended to challenge stereotypes, eradicate discrimination against disabled people and build capacity and participation opportunities for disabled people. The latter is particularly relevant in context of the current Departmental guidance on Personal and Public Involvement (PPI) in health and social care as a key component of quality health and social care provision (DHSSPSNI, 2007).

At a local level, the *Bamford Review (2002-2007)* of mental health and learning disability law, policy and provision in Northern Ireland is of particular relevance to the current study. Re-settlement from hospital into the community, stepped care models and person-centred planning are key recommendations from the Bamford Review that are now well integrated into more recent health and social care policies. With regard to learning disability, the Equal Lives report (Bamford Review, 2005) addressed a range of issues relevant to the lives of learning disabled young people and recommended improvements in: emotional and practical family support services; multi-agency working; joint planning and bidding at Departmental level; and more inclusive mainstream social and leisure opportunities. Transition to adult life was also highlighted in the review:

“Transition from school to adult services is a particular area of concern for parents. Commissioners and service providers are failing these children by not providing the same range of services and choices that are open to non-disabled young people, such as career guidance, further education, work experience and vocational training.” (Bamford Review, 2005: 34).

This review was comprehensive in its coverage of issues affecting both children and adults however many of the recommendations for improvement, including those focused on transition to adult life, have yet to be fully realised (Lundy et al., 2012; McMahon and Keenan, 2008). The DHSSPSNI's (2012a) evaluation of the 2009-2011 Bamford Action Plan indicated areas for continued progress including the need to develop advocacy services and greater choice of post-transition college courses. The latest report from the Children with Disabilities Strategic Alliance (2012) also identified areas that require further attention at policy and practice levels including improvements in the strategic co-ordination of services during the transition to adult life, home-based supports that promote independent living and post-school further education, employment and training opportunities.

Another major development in the past decade has been the *Carers and Direct Payments (Northern Ireland) Act (2002)* which enabled carers to have an assessment of their own needs and for the outcome of this assessment to influence service provision. Direct payments are often associated with a re-balancing of power from state paternalism to service user choice, control and empowerment (Smith, 2010). However, the uptake of direct payments among people with learning disabilities and their carers is low in Northern Ireland (Lundy et al., 2012). Following the Bamford Action Plan, a pilot of a self-directed support model is underway and aims to inform how personalisation could be mainstreamed in areas such as transition. However, within the context of current welfare reform initiatives, there are fears that the personalisation agenda will become an opportunity for efficiency savings and the retrenchment of statutory support for disabled people (Lawton, 2009; CDSA, 2012).

In relation to transition, a range of strategic developments can be noted over the last decade. An Inter-Departmental Transitions Group outlined a range of actions to improve the transition process for young people with special educational needs including: restructuring careers and guidance services; expanding the range of further education and employment programmes; developing person-centred day care alternatives; and increasing funding for life skills training and transition co-ordinator posts (OFMDFM, 2006a). Another inter-departmental and cross-sector initiative, the Promoting Social Inclusion (PSI) Working Group commissioned a survey of disabled people which identified core priorities for future policy development in Northern Ireland including: a fuller range of post-school training and employment opportunities; co-ordinated educational, social and recreational services at transition to adult life stages; and more support for disabled people to live independently in their own homes (OFMDFM, 2009).

In 2005, the Northern Ireland Housing Executive published the *Supporting People Strategy 2005-2010* which aimed to inform the commissioning of housing support services in accordance with prioritised need and value for money (NIHE, 2005). With regard to learning disability, the main focus of the Strategy was on the re-settlement of disabled people from hospital and residential settings rather than the



particular needs of young people making the transition to adult life. Indeed, a review of the Supporting People programme across the UK in 2010 found limited evidence of outcomes for service users and concern about unmet need for various groups, including disabled people (ECNI, 2012).

The Autism Act (NI) 2011 is the most recent addition to the disability legislative landscape in Northern Ireland. It has two key components aimed at enhancing services for people with conditions on the autistic spectrum. The first is an amendment to the Disability Discrimination Act 1995 to ensure the term ‘disability’ includes autistic spectrum conditions. The second is the implementation of an autism strategy which encourages more inter-departmental working with a duty to cooperate to implement aspects of the strategy. Developing awareness of autistic spectrum conditions and staff training initiatives are also core aspects of the strategy which is to be monitored and updated at regular intervals with reports to the Assembly every three years.

Three strategic disability policy documents have been recently issued: the *Learning Disability Service Framework 2012-2015*; *Physical and Sensory Disability Strategy 2011-2015*; and *Disability Strategy 2012-2015*. The Learning Disability Service Framework 2012-2015 specified requirements for transition plans before young people reach their 15th birthday and transition arrangements by their 18th birthday. The framework also emphasised: co-ordinated services; annual carer assessments; disabled people’s participation in decisions affecting their lives; and provision of accessible information, self-direct care options, and advocacy services. Both the Learning Disability Service Framework 2012-2015 and the *Physical and Sensory Disability Strategy 2011-2015* highlighted the need for greater access to: support for employment; meaningful day opportunities; information and advocacy; housing options; and transition supports. Joint working, person-centred planning and standardised approaches to assessment and recording across Trusts were also recommended (DHSSPSNI, 2011; 2012).

The *Disability Strategy 2012-2015* aimed to provide a framework for the implementation of the UNCRPD and addressed issues affecting disabled people and their carers across the life course, including a strategic priority to transform the process of transition to adult life for young disabled people (OFMDFM, 2013). Strategic priority ten focused on transforming the process of transition to adult life for young, disabled people. This is clearly a broad and wide ranging goal that requires more detailed policy and practice recommendations in order to ensure it is operational. The Equality and Human Rights Commission’s (ECNI & NIHRC, 2012) response to the Disability Strategy expressed concerns that it adopted a welfarist perspective with a focus on needs rather than rights and, with regard to transition, recommended the “development and resourcing of coordinated, person-centric, transition services across Northern Ireland” (ECNI & NIHRC, 2012:3) alongside increased employment opportunities for disabled people. Work is underway on an action plan and monitoring framework to support the implementation of the Strategy and the associated UNCRPD. This monitoring plan will need to explicitly allocate clear responsibilities and governance and delivery mechanisms to ensure its effective implementation and measurement of progress.

A Decade of Child Care Policy

A major landmark document in child care policy in the last decade is the *Ten Year Strategy for Children and Young People 2006-2016* (OFMDFM, 2006) aimed at improving outcomes for all children and young people over the ten year period. The

strategy identified six high level outcomes for children and young people to be: healthy; enjoying, learning and achieving; living in safety and with stability; experiencing economic and environmental well-being; contributing positively to community and society; and living in a society which respects their rights. The related action plan (OFMDFM, 2008) identifies key outcomes in relation to disabled young people's transitions including: improved support to live in the community; enhanced short break provision; the resettlement of all children living in learning disability hospitals into the community; reduced waiting time for wheelchairs and speech and language therapy assessments; and increased opportunities for training and supported employment.

It is interesting to note that other themes in action plans that have particular relevance to the lives and experiences of disabled children do not address their specific needs. For example, poverty is addressed within the theme of economic and environmental wellbeing but makes no specific reference to disabled children who are a group particularly vulnerable to poverty (Monteith et al, 2009). In addition, consideration of access to play under the outcome of enjoying learning and achieving ignores the significant barriers to accessing play opportunities for disabled children and young people in Northern Ireland (CDSA, 2012; UNCRC, 2008). Such omissions indicate that disabled children and young people are addressed in political and organisational silos rather than being comprehensively included across all statutory and government organisations and departments and in relation to the six main strategy outcomes. Whilst there is a need for an updated action plan and review of progress on outcomes for children and young people, the outcomes statements of this strategy document continue to influence current policy and practice developments, such as the ongoing work of the Children and Young People's Strategic Partnership.

In 2008, as part of the reform of children's services in Northern Ireland, the Department launched the integrated UNOCINI assessment framework, including thresholds of need and intervention (DHSSPSNI, 2008a, b). The Departmental guidance on this assessment approach makes specific reference to the particular needs and circumstances of disabled children and their participation is explicitly promoted (DHSSPS NI 2008). The guidance also notes that professionals should have knowledge of the impact of disability and on the identity-related needs of disabled children and their emotional wellbeing.

As part of the continued process of reform, the cross-sector, multi-agency *Children and Young People's Strategic Partnership (CYPSP)* was established in early 2012 to focus on improving outcomes for children and young people in Northern Ireland. The work of the partnership led to the development of six regional sub-groups planning for various groups of children and young people, including one sub-group on transition and another on disabled children. These sub-groups have recently published action plans and indicators for measuring outcomes from 2011-2014 based on the six key outcomes statements from the Ten Year Children's Strategy. The transition related action plan (CYPSP, 2011) acknowledged poorer outcomes for disabled school leavers. The importance of early transition planning was emphasised alongside the need for continued access to services as children move into adult services. The action plan recommended the development of passports and integrated, multi-agency, person-centred plans to improve the experience of transition to adult services for disabled young people and their families. These integrated plans are intended to capture the range of services required and the potential multiple needs of a disabled young person



as they transition to adult services. Passports will contain key information about the young person, including the involvement of all relevant organisations. The action plan also recommended: an integrated commissioning statement; a review of short break provision; a tracking system to monitor people's education, employment and training status; and the establishment of a regional multi-agency group to examine the development of day opportunities for disabled people. The children and young people with disabilities action plan (CYPSP, 2011a) also highlighted: the prevalence of disability hate crime; lack of counselling, peer mentoring and advocacy services; and limited opportunities to learn about personal safety and personal relationships.

A Decade of Education Policy

The *Special Educational Needs and Disability (Northern Ireland) Order (2005) (SENDO)* extended the remit of the Disability Discrimination Act to include education and promoted mainstream education for disabled children. Under SENDO and the associated *Education (Special Educational Needs) Regulations (NI) (2005)*, the first annual review after the child's 14th birthday, and any subsequent reviews, should include a formal transition plan, drawing together information from a range of individuals to plan transition to adult life, including the local Trust and careers services. The Board should also inform the Trust of the expected school leaving date between 8 and 12 months in advance. The content of the transition plan was clearly specified, including: curriculum needs at school to prepare for transition and learn adult life skills; multi-disciplinary and inter-agency working; transfer of information to adult services; opportunities for further education or employment; changing family support needs; and information and advocacy for the young person. SENDO and the *Supplement to the Code of Practice (DENI, 2005)* also clearly emphasised the importance of involving young people in assessment and review processes and taking their wishes and feelings into account. However, concerns about lack of resources, planning and support to implement SENDO have persisted (McMahon and Keenan, 2008; RNIB, 2006). Horgan et al (2010) found that young people with special educational needs were still a specific group at higher risk of being excluded from education, employment or training opportunities. Likewise, the UNCRC (2008) expressed concern at the marked differences in educational outcomes for disabled young people that showed the persistence of significant inequalities and compromised educational rights. In addition, the Equality Commission (2010) recommended amendments to SENDO (2005) to provide better protection against discrimination and harassment for disabled pupils in schools and enhance their right to reasonable adjustments and necessary supports to reach their educational potential. Plans for the reform of special education provision are underway and are likely to impact on future transitions for disabled young people (DENI, 2009). Indeed, there is much concern about the initial proposals to increase reliance on school-based provision and reduce the number of reviews of special educational needs (ECNI, 2010; NI Assembly, 2010).

New Policy Directions

Two major policy reforms are currently underway in Northern Ireland and likely to have a significant impact on the lives of disabled people: the implementation of the review of health and social care in Northern Ireland; and welfare reform.

In response to increasing demand on services, due partly to growing health inequalities and an ageing population, the recent review of health and social care in Northern Ireland, *Transforming Your Care*, proposed a vision for the future enhancement of

services (DHSSPSNI, 2011a). The review prioritises prevention and community-based provision, outcomes driven population-based planning, integrated working, safeguarding and personalisation. Recommended changes are aimed at ensuring services are sustainable, innovative and value for money. In relation to transition, the review recommends: the closure of long-stay learning disability and mental health institutions by 2015; further development of a variety of age appropriate community and short break services; improved access to information and peer and independent advocacy services; and increased the uptake of direct payments for people with learning disabilities. The review is likely to lead to major changes in the funding and organisation of health and social care services that could create opportunities for more creative and diverse approaches to service provision for disabled children and adults. For example, more joined up planning and delivery of services, shared budgetary arrangements, increased short breaks and enhanced community-based services. In the context of reduced public spending, however, the extent to which the diverse needs of disabled young people in transition to adult life feature in priorities for service development remains to be seen.

The *Welfare Reform Bill* is the second major policy shift currently underway which will introduce significant changes to social security benefits available to disabled people. Personal Independence Payments for people of working age (16-64 years) will replace the Disability Living Allowance and be subject to annual review with an intention to reduce spending. In the context of growing living costs, recession and welfare reform, the financial circumstances of disabled people in Northern Ireland are likely to be negatively affected (Lundy et al., 2012). Some commentators have also noted the possible impact of welfare reform and the current economic climate on attitudes towards disabled people and their vulnerability to abuse (Ipsos Mori, 2011).

Summary

A range of legislation and policy in Northern Ireland is aimed at promoting the rights of disabled young people as they transition into young adult life. However, there are fundamental financial and attitudinal issues detrimentally impacting on the lives of disabled people. The continued compartmentalising of disability, child and adult services presents a significant challenge for disabled young people in transition in Northern Ireland. Traditionally, services for disabled children and young people have been managed within disability programmes of care or dispersed across several programmes of care which impacts on assessment of need and strategic, integrated planning. In addition, the contrast in the mode of service delivery from targeting need in children's services to impairment-based programmes of care in adult services constrains the integration of services for disabled people and fails to meet the diverse and complex needs of those crossing service boundaries during the transition to young adult life.



In the context of the current economic climate and the political emphasis on local decision-making, the struggle for targeted and protected budgets for disabled young people in transition may become even more challenging. Services are under increasing pressure with cuts in public sector spending, potential adverse effects of the reform of welfare and health and social care, and an increasing population of disabled young people with a range of needs. In this context, political will, strong leadership, performance management structures and ring-fenced funding will be required to ensure the effective implementation of legislation and policy for disabled young people in transition to adult life.



2. METHODOLOGY

The current study aimed to explore young learning disabled adults' transitional and early adult life experiences using a mainly qualitative approach methodology incorporating case file reading, semi-structured interviews and biographical narrative techniques (Denzin & Lincoln, 2000). This section of the report provides further details on the methods used and ethical issues relevant to the research approach.

2.1 Research Aims and Methods

The aim of the research was to investigate the transitional and life experiences of young learning disabled adults. The objectives were to:

1. Investigate the experiences of young learning disabled adults and their identity narratives;
2. Explore the impact of services on the lives of young learning disabled adults;
3. Identify the type and range of service options available for young disabled adults; and
4. Elucidate key challenges for service providers seeking to meet the needs of young disabled adults.

Individual semi-structured interviews were undertaken with ten young learning disabled adults, their main carer/parent and social workers from adult learning disability services in four of the five Health and Social Care Trusts in Northern Ireland (reflecting the geographical areas in the first study before the restructuring of Trusts). In addition, interviews were undertaken with transition co-ordinators, team leaders and senior managers (n=10), voluntary sector managers (n=5) and senior personnel at policy and commissioning levels (n=3). Semi-structured interviews were the most appropriate method for this study as they allow for in-depth exploration of the subtle meanings and complex experiences of individual respondents. Interviews explored participant views and experiences of transitions and the impact of post-school decisions and services on the lives of young learning disabled adults. Interviews also addressed the challenges for parents and service providers in meeting transitional support needs and sought to identify any examples of good practice initiatives.

In addition to interviews, the researcher read adult social care case files, with prior consent, to gather documentary information about services used over the past decade. This information allowed the researcher to contextualise interview questions and provided an opportunity to triangulate information across three data sources (young adults, parents and case file records). This helped with clarification of specific details that parents or young adults had difficulty recalling. It is recognised that using case files as a source of data needs to be approached with caution as they may contain inaccuracies, incomplete or contradictory information or information that is biased to provide a justification for action taken (Denscombe, 1998). However, case files did provide information about access to services over the years and how professionals dealt with the case (Hayes and Devaney, 2004). Consulting case files also provided an opportunity to consider the types of information that are recorded and the extent to which assessment, care planning and review documents are held on file. The researcher was also interested in identifying whether the views of young adults have been recorded in the case files as part of transition planning processes.

Recruitment of Participants

Participants were selected from a sampling frame of 21 young adults who had participated in the earlier study (2000-2002) who were now aged 18 years and over (discounting deceased and closed cases) (Kelly, 2003, 2005, 2007). Given the ten year time lapse, seven young adults had moved to other jurisdictions or no longer had contact with social care services. In these cases, letters of invite were sent to the last known address but no response was received. In four cases, consent was refused mainly due to a current family/health crisis or a reluctance to revisit past experiences (for example, one young adult had since moved into public care). A total of ten young adults agreed to participate which represented almost half of the original eligible sample. An overview of the age and gender of young adult participants is provided in the table below and a summary profile of each young adult is provided in Appendix Two.

Table 1: Age and gender of young adult participants

	Male	Female	TOTAL
18-21	2	1	3
22-25	1	3	4
26-29	1	2	3
TOTAL	4	6	10

The key workers for the selected cases were also recruited to participate in interviews. These key workers were all social workers working in adult learning disability teams. Additional interviews were undertaken with transition co-ordinators, team leaders and senior managers to gather data on transitional arrangements and strategic developments across Northern Ireland.

Interviews with Parents

The main parent of each young adult who was involved in the earlier study was interviewed. In all cases, these were mothers, however, two fathers joined in discussions with the researcher following interviews. Interviews with parents were held before engaging with the young adult in the research process. This initial contact with parents allowed for the collection of information about any changes in circumstances in the family since the previous study and any significant events in the young adult's life (e.g. family bereavement). In the previous study, it was beneficial to have this background information to help the researcher construct sensitive questions for the interview with the disabled young person.

Interviews with parents explored their views of their son/daughter's life experiences since the previous study, including their home and social life, education and employment opportunities, relationships with professionals, and the provision of support services to meet their changing needs. Interviews also explored the current situation for parents and their son/daughter, including needs, availability of appropriate support services and any experiences of good practice.

Interviews with Young Disabled Adults

Interviews with young adults explored the changes in their lives since the previous study, how they viewed themselves and their current life experiences. Biographical narrative techniques were also employed to enable young adult participants to explore



their life experiences over the last decade. Social researchers contend that retrospective narratives tell a great deal about the person and their understanding of the social world (Denzin and Lincoln, 2000). The researcher made efforts to tailor the interview process to the participants strengths and communication preferences including the use of a visual life story book, photographs and signs or symbols (e.g. feelings faces) (Kelly, 2007). As some participants had difficulty understanding the concept of time, the visual life story book and photographs helped to explore the chronological order of their experiences and followed the journey of the young adult from the last time the researcher met them to the present day, identifying significant people and events.

Themes were used to guide the interviews including: all about me; my home life; my social life; my weekdays and weekends; my personal life; and my hopes and dreams for the future. The researcher also offered participants the opportunity to use a digital camera to take photographs of key places or people in their lives which acted as prompts for discussing their current life experiences and self-identities. Half of the sample chose to use photographs with some preferring to use their own camera or photographs they had already taken to put together a photographic collage. In the previous study, the researcher visited the young people at least two times to undertake interviews so the same approach was offered in the current study. However, a small number of participants preferred one longer interview instead of two visits.

Interviews with Professionals

Finally, semi-structured interviews with key workers focused on their experience of supporting disabled young people in their transitions to adult life. In addition, interviews with other professionals and managers enabled the researcher to gather data on organisational and Trust policy issues. Interviews also explored the challenges for service providers in meeting the needs of young learning disabled adults and sought to identify any examples of good practice.

Data Analysis

Interview data was analysed through an inductive and systematic analytical process, grounded in the accounts of research participants. With prior consent, qualitative interviews were recorded and transcribed verbatim. Transcripts were read and re-read to enable immersion and rigorously analysed by a process of data reduction, display and conclusion drawing (Guba and Lincoln 1985). Common themes were identified by a constant comparative approach coded and organised with the assistance of the MAXqda qualitative software analysis package. Case file audit records were analysed separately at early stages of the study to inform interviews. Descriptive data from this analysis were stored anonymously and merged with qualitative data from the interviews with respondents at final stages of analysis for cross-comparison purposes.

Advisory Groups

A professional advisory group was established to guide the study from the outset. The membership of this group comprised a representative from: the DHSSPSNI; child and adult social work services in the non-participating Trust; the voluntary sector; academia; and a parent/carer. This group met four times during the course of the study to advise on: recruitment and methods; the analytical strategy; and recommendations for policy and practice.

A young adult advisory group comprising of members of the Barnardo's NI Sixth Sense Children and Young People's Participation Group was also established and met four times during the course of the study to advise on the accessibility of proposed research methods and assist in the identification of themes emerging during data analysis. The group also assisted with the identification of themes emerging during data analysis and the development of a DVD to disseminate the findings.

2.2 Ethical Considerations

The study was approved by the Office of Research Ethics Committees Northern Ireland (ORECNI) and undertaken within the guidelines of the health and social care research governance framework. The ethical issues pertinent to this study included gaining informed consent or assent, confidentiality and the risk of causing emotional harm.

In order to protect the anonymity of young adults and their parents, Health and Social Care Trusts forwarded information about the study to parents/carers and young adults on behalf of the researcher in a range of accessible formats. The researcher had the name and date of birth of the young adult from the previous study and the local Trust used this information to identify the young adult. Only parents and young adults who returned the reply slip to indicate interest in the study were contacted directly by the researcher to explain the research in more detail and seek consent. If young adults were deemed to lack capacity to provide informed consent, the researcher sought the assent of both parents and young adults. Consent was also viewed as a continual process open to re-negotiation as the research progressed by offering participants opportunities to choose not to answer some questions and change their mind about taking part. The professional boundaries of confidentiality were explained at this consent stage, including the duty of the researcher to disclose information necessary to keep young adults and others safe. Data handling, storage and security met ethical standards and guidance under the Data Protection Act (1998).

The researcher was also aware of the danger of causing emotional harm to participants. This could be distress, hurt, anger or worry related to questions asked or sensitive or personal issues discussed. Careful wording of questions, effective use of interpersonal skills and providing opportunities for respondents to discuss thoughts and feelings helped to minimise this risk. Information about organisations or professionals was also provided for those who wished to access further support related to issues raised. In addition, young disabled adult participants were offered the option of having someone else present to provide support for them during their interview. None of the young adult participants requested this although some of them involved their parent at the start or end of interviews.



3. FINDINGS

This section reports on the main findings of the study. These are organised under five core themes: transitions; post-school options; social exclusion, disability and identities; adult services; and the organisational and policy context. Quotations from interviews are integrated where relevant to illustrate key themes. When referring to young adult participants, pseudonyms are used to protect the identity of individuals.

3.1 Transitions

The main focus of this study was to explore the transitional process for young adult participants. The findings provide insight into the types of support they received during the transition to adult life, levels of participation in decisions about post-school lives and post-transition outcomes experienced. Another key theme in the findings relates to the role of parents and the transitions and challenges they experience as their son/daughter moves into young adult life. This section reports on these findings and also incorporates the perspectives of professionals who provide support for disabled young people as they move into young adult life.

3.1.1 Young Adult Transitions

Each of the four Health and Social Care Trusts involved in the study had their own transition arrangements as outlined in Appendix One. Trusts that did not have designated transition co-ordinators operated a system of planning for those expected to leave school whereby the key worker based in children's services worked closely with schools and was expected to make referrals to appropriate adult services and, in some cases, co-work with a key worker in adult services. Trusts with designated transition co-ordinators (who were trained social workers usually working part-time hours) based these posts within children's services. In one of these Trusts, the transition co-ordinator was on maternity leave and funding was not available for a replacement.

Transition Co-ordinator Role

The role of the transition co-ordinator varied from liaison with community networks to direct transition planning and support for young people and their families. In one of the Trusts, the position was a relatively new post at senior practitioner level holding responsibility for children with all types of impairment. The transition co-ordinator focused on developing networks with other services and agencies in the community and providing day-to-day support for young people in transition. They also engaged in collaborative work with education transition co-ordinators, further education colleges and adult services to forward plan for services in young adult life, including identification of support needs and available day opportunities. In this Trust, the transition co-ordinator role extended until young adults were 25 years old although key workers from adult services were invited to attend the last annual review at school and engage with the young adult once they were 18 years old and children's services ceased. The transition co-ordinator met at least twice yearly with the adult services Team leader to review cases due to transition within six-twelve months or earlier for more complex cases. The Team Leader in this Trust was very positive about the role and contribution of the transition co-ordinator in relation to identifying new sources of support in the community and promoting person-centred planning.

In the other Trust, the post was not at Senior Practitioner level and the service was only for young people aged 14-19 years. As in the other Trust, the transition co-ordinator worked very closely with education transition co-ordinators and schools, preparing young people for school transition planning meetings and attending transition meetings on an annual basis. In this Trust, forums were also established to facilitate multi-agency working and communication of issues to senior managers. Cases due to transfer to adult services are identified two to three years in advance and efforts are made to engage with adult services six months prior to 18th birthdays although sometimes adult services do not have any input until post-18 due to high caseloads. The transition co-ordinator in this area suggested that extending the role beyond 19 years would be helpful as it takes time for transitions from school to settle and more changes occur in the early twenties.

Transition co-ordinators were in an unusual position because they did not hold a caseload of their own but co-worked with key workers from child and/or adult services. They kept their own records on contacts with young people but were expected to input core records onto the Trust's electronic database and share updates with the relevant key worker, usually by email. This may explain why transition plans or contact between transition co-ordinators and service users was often missing from case files. With this dual approach, there is also potential for role diffusion between transition co-ordinators and key workers with lack of clarity about who should undertake person centred transition planning. It is important that the role of the transition co-ordinator is clearly specified and understood by both child and adult service teams.

Transition co-ordinators emphasised the importance of their role in relation to developing links and coordinating resources in the community and across sectors. However, they were concerned that this aspect of their role was often neglected because of the demands on their time for individual transition support. Interestingly, some senior managers did not recognise this aspect of their role, and viewed their main purpose as guiding young people to the most appropriate day opportunity.

There was some concern that the transition co-ordinator role focused on particular groups of young people or solely on education rather than other transitional needs which created inconsistencies in transition support. For example, the main focus of the transition co-ordinator varied from physical disability to those with high-level needs:

The transition worker within the children's world would have been involved in people moving from school to day care... rather than day opportunities... we were taking cases coming up to 18 years of age with no involvement of the transition worker... so there was no broad consistency.

Some professionals suggested that the transition co-ordinator offered consistent support whilst the allocation of key workers in adult services is still being arranged. However, others were unsure about their role and the potential to put pressure on families to work with a new professional for a short period at an already difficult time of transition. One key worker in adult services explained they preferred to provide transition support, rather than refer to a transition co-ordinator, because it was part of their role and relationship with the young person and their family:



It makes sense that if I am working with a family for quite a number of years and know them, I do that... why would I stop and say to a family, go on over there to the transition co-ordinator for that? What's the point putting that family with a strange key worker for 6 months? They are coming to my caseload anyway.

It was also noted that transition planning often highlights other additional needs of the young person or their family that will need to be referred to the key worker anyhow for follow up support.

The transition co-ordinators in both Trusts recommended the establishment of transition teams to provide a more comprehensive service rather than one individual attempting to oversee a large number of young people's transitions alongside a developmental role. Indeed, a third Trust had piloted the position of a transition co-ordinator and found that the workload was too heavy for one person. When the issue of a transition team was explored with other professionals, concern was raised about potential duplication of roles or the creation of further transition points as young people move from the transition team to the adult services team.

Experiences of Transition Planning

Three of the young adults involved in the study had access to a transition co-ordinator. In two of these cases, the transition co-ordinator worked closely with the young adult, their family, the school and post-school services to develop a transition plan. Whilst, the parents of these young adults were pleased with the transition planning process, they were very dissatisfied when none of the agreed plans were implemented on the young adult's departure from school. In addition, the support from the transition co-ordinator ceased when they left school. Similarly, the parents of a third young adult had input from a transition co-ordinator at home and at school transition meetings but were dissatisfied with the outcomes of these meetings as they did not feel they had access to adequate information and advice about post-school options.

School based transition meetings were held for most participants, usually involving a parent, school staff and the key worker or transition co-ordinator. Occasionally, key workers from children's services also made a home visit to discuss post-school arrangements. These meetings were recorded in case files as contacts with families rather than comprehensive or person-centred transition plans. They often did not involve the young adult and rarely involved staff from adult services.

Although all of the participants had a named key worker from children's disability services, there was no record of a person-centred transition plan undertaken by social services in any of the case files read. Indeed in the majority of cases, aside from involvement in school-based meetings, limited work had been undertaken by social services to plan for the transition from school to adult life. For example, Edel's key worker was on leave during her transition years and the only record in her case file regarding transition was an invitation to the key worker to attend the first school transition meeting. Given this lack of key worker and transition support, it is interesting to note that she was the only young adult in the study not availing of any adult services and spent all of her time at home. With more transition support and information about a fuller range of day opportunities, perhaps she could have availed of more services in her young adult life.

Likewise, Natalie and her family had very limited involvement from social services during her teenage and transition years and her case file did not contain any information about transition planning. The only record of transition planning for Ronan was a school meeting which recommended he should stay at school until he was 19 years old when he would transition to the day care centre. Similarly, Laura had a 14+ school review and transition planning meeting which outlined plans to integrate independent living skills and work placements into her school programme. However, there were no further records of transition planning for Laura.

Access to Key Workers in Adult Services

Young people were not only transitioning from school to a new day opportunity, they were also moving from child to adult services and unless both transitions were considered and managed carefully, the transition process was often fragmented. Access to adult services as early as possible was critical, particularly in relation to securing resources to meet identified post-school needs. When access to adult services was not arranged, transition plans were not well implemented, leaving young people and their families feeling very uncertain about post-school lives.

Involving adult services at early stages of the transition planning process helped to ensure that resource issues were clearly discussed with families and realistic plans were made for those requiring extensive packages of care. Access to day care placements for young adults with complex needs was a key issue for resource allocation. Places were often full or staffing levels were inadequate, therefore, early planning and knowledge of the upcoming demand for services was critical for service providers. Some Trusts found it useful for adult services to engage at an introductory level whilst young people were still at school and receiving children's services:

Our children's services continue involvement until they leave school... but there is an investment from adult services to get involved in those years, not only to make sure we know the profile of need coming is but also to try and shape your services.

Most Trusts had mechanisms in place to help identify the incoming population of young people to adult learning disability services. In some areas, these systems were working well however, in others, these were not well established and needed further development to assist with service planning:

At the 16 age group, we would love a profile of what is coming in the next four or five years... at the minute it is not planned.

Prompt re-assessment for entry to adult services and a co-ordinated transfer to the newly appointed adult services key worker who could process referrals to relevant adult services was an essential aspect of successful transitions. The main reason why key workers were not allocated at an early stage was the age requirement for access to services and the need for an assessment to confirm eligibility for adult services which can take some time:

We would still have a number of referrals that come to us after people are 18 and some of that is needing to have confirmation of a learning disability diagnosis, so there has been a referral to psychology for an



assessment then it comes back to children services to then be referred to us. We may have known about them theoretically but we've not been involved with them.

In addition to these requirements, many adult service teams were under-resourced in terms of staffing and had to prioritise cases for key worker allocation. As a result, the process of accessing a key worker in adult services was often disconnected from the person-centred or transition planning process undertaken as young people left school.

Some young adults had experienced breaks in services during the transition period due to lengthy delays in the transfer to adult services or the re-allocation of key workers. In these situations families were left unsupported and often had to proactively follow up with service providers. In some cases, parents had become so frustrated at the lack of post-school planning or service options that they wrote letters of complaint or sought support from community representatives or agencies. These were usually responded to promptly but did not always lead to an improvement in access to information or services. For example, Callum's parents contacted social services when he was 16 years old seeking access to short break support. A staff member conducted an assessment and made a referral for a short break service and allocation of a key worker. He was placed on the short break waiting list and was not allocated a key worker due to capacity issues within the service. Despite repeated requests from his parents, two years after these initial referrals were made, they were still waiting for a response regarding the allocation of a key worker and still had no access to short breaks despite significant stresses within the family home. When he was leaving school at 18 years old, a meeting was then held with a representative of the adult disability team, the day care manager and the transitions co-ordinator. It was recommended that Callum should access a five day placement involving centre based activities and day opportunities in the community. However, due to resource constraints, only a two day placement in a day care centre with a phased transition was secured. The transition co-ordinator retired and was not replaced and his family were left with no support and no key worker to take the transition plan forward. His parents wrote a letter of complaint to their local Trust which was then acted upon as their case was re-considered as a priority for key worker allocation.

Sarah, who has complex behavioural and health related needs, had a similar experience. A transition meeting in her last year at school when she was 18 years old recommended a full-time adult day care placement. At this meeting a five day placement was confirmed but a start date could not be finalised due to limited funding and staffing levels in the day centre. Sarah's social worker and teacher met again at the time of her departure from school and agreed short induction visits to the local day centre. Induction began, however Sarah waited ten months for a two day placement. During this time her mother struggled to maintain her carer role with no support and was forced to cease employment. A year later, a carer assessment highlighted the severe stress on Sarah's mother and recommended urgent provision of a five day placement in day care. It was another nine months before a three day placement was secured and a further nine months for a five day placement.

Robbie and his parents also experienced breaks in service provision. When Robbie was 16 years old, a transition review was held at his school involving Robbie and his parents, his social worker, school staff and the transition co-ordinator. In the absence

of training and employment options in the local community, it was decided that Robbie would pursue a college course. Following the commencement of his college course when he was 17 years old, he had no further contact from his key worker or transition co-ordinator. The family received a letter confirming a referral to adult services following his 18th birthday however they had no follow up contact from adult services. Robbie finished his college course and could not access day opportunities during the summer months because the referral to adult services was not yet processed. Robbie's parents also wrote to the Trust complaining about the lack of support he had received and received a prompt response explaining that the case had been allocated to a key worker who had been on leave and there were no resources for staff replacements. A transition review was then held when Robbie was almost 19 years old. At that stage he was enrolling for a new college course and needed information on transport options and opportunities for further work experience. It was agreed that a home visit would be arranged and a referral would be made to day opportunities however, this referral was not processed until a year later. Fortunately, when a new key worker in adult services was allocated Robbie was referred promptly to day opportunities and a local training placement. However, the intervening period of no key worker contact left Robbie and his family with no information or support at a critical transition period when he was still making decisions about the next steps in his post-school life and required social support.

Two families experienced consistency in key worker services and reported higher levels of satisfaction with the transition process. These young people were promptly referred to adult services and allocated to a new key worker who was introduced to the family before children's services ended. Interestingly, in one of these cases, the young person's mother did not feel well supported by the school but her social worker co-ordinated a transition meeting at the school which identified a range of alternative day opportunities. The case was referred to adult services the following year and the newly allocated key worker continued to support the family. Although in both cases there were no official transition planning documents held in their case file, it was clear that their social workers played an active role in the transition process. They had attended school transition meetings, provided transition support for the family and day opportunity providers and perhaps, most importantly, ensured that the allocation to a key worker in adult services was not delayed and quickly followed end of contact with school and children's services.

It should also be acknowledged that for some young adults, continued support from statutory disability services is not necessary when they have access to alternative supports from the voluntary sector or in the community. For example, when Lorraine left school she accessed employment support from a voluntary organisation. Her case was referred by children's services to the adult disability team for further support for independence skills. However, when her case was reviewed by the adult disability team, it was decided, following re-assessment, that she did not meet the requirements for the learning disability service. The case closure information on her file was very limited and contained no information about the re-assessment for eligibility to adult disability services however her parent explained they were happy with this decision as she was coping well and could still access employment support from the same voluntary agency.

Continued Transitions: Moving on and Feeling Boxed In

Reflecting the varied nature of contemporary life transitions, for many of the young adults, later transitions in their young adult lives were as pertinent as their move from



school or children's services. Service structures create transition points at 18 years for the move from child to adult services and again at 19 years when many learning disabled young people leave school. However, in reality, the life paths of young adults greatly vary and more important transitions often occurred later in their twenties. For this reason, study participants emphasised the importance of continued support for young adults as they made further decisions in their post-school lives. The need to build the capacity of young adults to make further life choices and to provide continued support for those requiring more intensive provision was also highlighted.

There are a lot of different times of transition, we are working around that first stage of transition but the next stage is probably more crucial as we move towards employment, further education... There is a lot of work put into that first transition, you do need some commitment to maintain that and ensure that the next stage is as smooth...

The young adults involved in this study could be grouped into three categories in relation to continued transitions. Firstly, there was a group of three young adults who were still moving on. Three young people had moved from school into a range of further education courses, training and supported employment opportunities. There was also a sense that their immediate futures were still being negotiated as current activities will soon come to an end and it is envisaged they will eventually move into supported or paid employment.

The second group of participants were also planning to make decisions about further changes to their day opportunities however, unlike the first group, these transitions were due to difficulties with service provision rather than changing needs. For example, two young people ceased participation in services that had begun to specialise provision for service users with more complex and challenging behaviour.

The remaining five participants are in a third group that seemed to be boxed into an established routine of service provision with few plans for further transitions. The lives of these young adults had stayed much the same since leaving school. In some cases, young adults wanted new experiences but were unsure what else they could access or how they would cope with changes to their current daily pattern of living. For others, there was a strong desire for change but no plans for transition were in development. For example, Edel wanted to engage in further social participation but remained at home. Similarly, Laura was very keen to leave her current day care service but there were no plans to source an alternative provider. Laura explained how she felt trapped:

There isn't anything... I have to go to the centre because they can't get me placed in a job... it just keeps on going. You don't move into something... Once you go there you stay until you're in your forties or fifties. You stay there until you die.

These findings suggest a need to more seriously consider continued transitions in young adult life and move away from service created transition stages to person-centred transition supports that promote opportunities for learning disabled young people to continue to fulfil their potential and engage in day opportunities that meaningfully address their changing needs.

Summary

Different approaches to transition planning and support were undertaken across Trust areas. Some had designated transition co-ordinators and others considered transition support to be part of the key worker role. There is some confusion about the role of transition co-ordinators which has led to concerns about duplication of efforts or young people not receiving continued key worker support. Disabled young people and their families want a smooth referral from child to adult key worker, person-centred transition planning that is connected to available adult services, and reduced waiting times for information about eligibility for access to adult services. Participants often desired or experienced further transitions in their twenties therefore, continued and co-ordinated transitional support is critical to enable disabled young people to reach their full potential in young adult life.

3.1.2 Participation in Decisions about Post-School Lives

Two of the young adult participants were actively involved in decisions about post-school activity, including finding out about opportunities and making decisions about which option to pursue. One of these young adults continued to make changes in her early adult life, moving from college into several work placements and eventually paid employment. However, for most young adults, decisions about post-school lives were made for them by other adults as Laura succinctly explained:

Most of it was taken out of my hands... I couldn't go for a proper job so they wanted to put me in the centre so what was the point in me saying anything.

Usually parents made these decisions based on guidance from professionals (school staff, transition workers or social workers) or based on their own research into post-school options due to a preference to access alternatives to traditional day care. Parental decisions were made in the context of eligibility and availability of services and often centred on concerns about levels of suitable care as much as opportunity for continued education or development.

Some parents encouraged the involvement of their son/daughter in choosing post-school activities but these were usually restricted choices based on decisions already made about the suitability of services. A few parents decided on two options and allowed their son/daughter to choose which one they preferred. In these cases, the young adult felt they had been somewhat involved in the decision about post-school activities. However, in most cases, parents decided on the post-school activity and then brought their son/daughter to visit it to show them why it was the best option. When young adults expressed a dislike for the activity or service, parents usually upheld their decision due to assumptions that their son/daughter did not understand that it was the most appropriate service from a very limited range of options available or just needed more time to settle in as one mother explained:



He knew he had to go there... it took a wee while for him to come around to it but then he was grand.

In some cases, young adults expressed a preference to stay at home when school finished and not participate in any activity in young adult life. Parents in these cases had encouraged their son/daughter to engage with post-school opportunities explaining that it was important for their own wellbeing to engage in constructive activities outside the family home and with their peers. For example, both Ronan and Maurice did not wish to continue attending college but their parents strongly encouraged them to re-enroll in courses to ensure they had opportunities for social interaction and further learning. These parental decisions were made with the best interests of their son/daughter in mind but do raise questions about the extent to which the rights of young adults to make their own life choices are exercised. This is a difficult ethical issue that parents and professionals must negotiate during transition from school and as early adult life progresses.

Parents often made decisions about post-school activity based on concerns about their son/daughter's limited understanding or inability to make informed decisions about life after school. In these cases, young adults experienced transitions to post-school activity as a sudden change rather than a planned move. Limited ability to make informed decisions about post-school activities was sometimes attributed to impairment effects but also reflected a lack of prior experience of participation in planning and decision making, restricted access to information about post-school opportunities and low expectations.

Having a Say about Services

When young adults had transitioned into adult services there was little evidence of involvement in decisions about further transitions however, there was some indication of involvement in reviews of services. This was particularly the case in day care or residential short break settings where young adults were invited to attend reviews and consulted about their experience of the service. For example, Maurice's mother described a positive experience of his involvement in a review meeting:

When the adult social worker took over she would spend some time talking with him... at that meeting they asked him how he was getting on there and Maurice said "It's boring". I thought 'Great you just speak up, son'. So it was very good and he was very much a part of the meeting...

Unfortunately, however, these experiences were rare and other participants were more reluctant to share their feelings and views of services at these meetings as Laura explained:

I go to all my reviews now... It doesn't make any difference.

I: Do you say that you don't like it and you want more things to do?

I probably don't because I'm scared... because the boss comes to them - and I'm like well I can't say this.

I: And do they give you space to say something?

Not all the time.

***I: Could you tell your social worker that you don't like being at the centre?
I couldn't tell her because she would go right back to them and tell them.***

On one occasion Laura shared that she felt bored at the centre and they responded by setting up a project with a volunteer to establish a centre magazine. Laura really enjoyed this experience but unfortunately it had to end when the volunteer left. This is a good example of how participation and having a say at reviews can help to enhance the quality of service provided for a young adult. However, Laura's story clearly shows that participation should be approached carefully and sensitively so that young adults feel empowered to have a voice and are listened to. It also indicates that young adults have limited prior experience of being consulted and involved in reviews of services. School systems and practices could develop this experience and the confidence of disabled young people to have a say by involving routinely in school planning and reviews.

Other young adult experiences of reviews of services suggest a heavy reliance on their parents and a lack of interest in the process or outcome of these meetings:

I go to and mum goes.

I: And how do they go?

Alright yeah... but I just do my own thing. I just get on with it.

Likewise, Callum's parents explained that he attended transition meetings almost by accident and did not play an active role in the process:

The transition meetings were supposed to be just for the adults but Callum thought he had to go too so he always came in and sat with us. And no one ever asked him to leave and we didn't either.

I: Did he ever say anything at them?

No, not too much I think he just sat day dreaming.

This level of involvement is unlikely to inform changes to services and is in danger of tokenistically having a young adult present but not meaningfully involved. It is important to adequately prepare young people for such meetings and provide opportunities for their views to be seriously considered.

Seven of the ten participants indicated that they were never or only sometimes involved in decisions. The other three young adults felt they were mostly or always involved however these decisions were usually related to daily activities (for example, using the computer or watching television) rather than decisions about services. For example, Maurice explained that he was consulted about use of his computer but was not involved in the decision that he would move from school to college:

I: What about going to college – who decided that?

My parents

I: Were you happy with that?

Probably not



***I: And do you think people didn't listen to you?
They didn't care about me.***

In most instances parents felt they acted in their son/daughter's best interests when they excluded young adults from some decisions about a service. In Laura's case, her parent had ceased contact with a service provider who had routinely failed to attend appointments and communicate with the family. As Laura felt she had a good relationship with this provider, she was annoyed that her mother had made this decision without consulting her which created tension in their relationship.

Several participants also recalled experiences when their ability to be consulted and involved in decisions was not recognised by professionals. These young adults felt their potential contribution had been undermined and this had an impact on the extent to which they were prepared to make efforts to participate in the future. Laura described her experience of professionals who helped manage direct payments:

***Those people are awful. I don't be at the meetings with them anymore...
They just didn't even think I could do anything or speak.***

In contrast, Natalie felt she was sometimes involved in decisions and indicated that she had learnt from mistakes she had made:

***I: So you have made decisions?
Yeah but sometimes I make mistakes and I learn from them and not do them again.***

Natalie makes a salient point that being involved in decisions is a key learning opportunity. This is part of the process of transition for many non-disabled young people who learn by experience as they move into young adult life that should also be afforded to disabled young people.

Experience of being involved in decisions at home helped to encourage disabled young people to have their say in other settings. Interestingly, as all of the young adults still lived in the family home with their parents, there were several aspects of their home life that were still controlled by their parents such as time spent on computers and bedtimes. Some of these non-negotiable house rules were related to parental concerns about risk but in other cases they were established routines that had been maintained since childhood without challenge or consultation as their son/daughter grew older.

Professional Perspectives on Participation

Some professionals had a clear sense of their duty to ascertain and listen to the views of young adults, using a range of techniques and approaches:

Within meetings you are hearing more of the parent, so you try to overcome those barriers, just because the young person can't communicate with you verbally, it is about getting their views down on paper and drawings or whatever way they want to communicate their needs.

Practitioners reflected that, although there have been major developments over the past decade regarding the participation of disabled people, there was also still some way to

go. For some social workers, this was due to the limited time available to develop close working relationships with disabled young people in transition:

It's something that needs to be further developed. You would love to be able to go in and have the opportunity to really get to know the young person and to do work with them with regard to the whole move which you don't.

Ascertaining the views of young, disabled adults sometimes required careful negotiation with parents and carers and needed to be paced appropriately. Indeed, there was a clear message from some professionals that in many cases parents were the main decision makers:

I don't think that they are involved in the decisions around what changes would be made, for example, daytime opportunities. I don't think their voice was heard... parents tend to be the main decision-makers. I think there is still a reliance on parents. Whenever we have reviews the young person would be there but the final decision comes down to what parents want.

This was a dilemma in cases where professionals had concerns about the impact of decisions parents made on the opportunities for their son/daughter and where there was little guidance on how to negotiate complex family dynamics. There was concern that challenging the views of parents had potential to damage working relationships and could lead some families to withdraw from essential services completely:

What is there to guide us in terms of when we put individuals' with the learning disabilities views absolutely to the front and walk away from the parents' perspective? If we are convinced that this is the best approach for the individual or maybe that should always be just a managed process which is how we currently do things because we can't damage or ostracise the relationship that we have built up over 20 years.

Parents were in a powerful position in relation to overriding the views and wishes of their adult son/daughter due to concerns about their vulnerability, despite professional efforts to uphold the rights of the young adult:

It's very difficult if you have parents who are used to making decisions... I'm just thinking of one young man who wanted to go back to day care and his Mum didn't... so he will be at home with his Mum... it's a very isolating situation... I did raise the issues with his Mum... but in that case he doesn't have a say.

In contrast, other professionals described practice approaches that prioritised the views of the young adult through early intervention with the family:

I would be visiting the young person and having conversations at home not just about leaving school but this is your adult life, it's about where you see yourself going and in terms of your family where you see that going, growing up and relationships. I would have had those conversations with the individual and the family.



Professionals from the voluntary sector felt they focused on the views of young adults however this sometimes meant challenging the decisions of statutory providers:

Our view is that obviously it is important that the parents are kept informed... the young person is central to the process... There is a challenge then for us to go back to the Trust and say we have concerns that the rights of this young person are not being met... where a parent and a social worker have made a decision that we don't feel is the best outcome for a young person we have challenged it...How far that goes is a challenge.

There was very limited information on the views of young adults or their involvement in decisions in case files although professionals suggested their views were recorded as part of the review process. Perhaps part of the reason for the lack of information held on file was that there was some ambiguity about who had responsibility for ascertaining the views of young people in transition when schools undertook transition planning and both key workers and transition co-ordinators were involved. Team Leaders were clear, however, that key workers should play the main role in facilitating the participation of service users in transition planning as they have built up relationships with young people over time and are familiar with their needs and communication preferences.

Summary

Whilst there is general agreement that disabled young people should participate in decisions affecting their post-school lives, key barriers to their involvement were identified including a need to: develop more creative ways for communicating and prioritising the voice of disabled young people; build their capacity to have a say through involvement in everyday decisions and early experience of participation; encourage disabled young people to feel empowered to challenge service providers and parents; and provide guidance for professionals on adult participation rights and negotiating complex family dynamics.

3.1.3 Parents in Transition

For most parents their son/daughter's transition to adult life is marked by a change in parenting role as they become increasingly independent. For parents in this study still undertaking caring roles for their adult son/daughter, the parenting role continued or became reframed into that of a carer, as one mother explained:

When the others have grown up that role changes when you don't really have a say in what they do... then you have more like a friendship role with them... but the role with Edel hasn't changed a lot as a parent, you still are looking after her and tell her to have a shower or clean your teeth and make sure she doesn't eat too much rubbish. So it hasn't changed really as a parent.

Continued caring roles had become a normal routine for most parents. However, ongoing personal caring roles were becoming more difficult as sons/daughters grew

physically and older carers developed their own health needs. In addition, some parents noted the impact of their continued caring roles on their own lives:

My social life is non-existent... she won't let anyone else put her to bed... Some days it is hard when you look at your friends and their children have grown up and you are still sitting here.

As a result of continued caring roles, some parents still viewed their son/daughter as a child needing their support and protection:

My role is still the parent because I still treat her by her mental age rather than her generation age... she totally relies on me for all her everyday things... to me she's still a needy four year old.

Some parents suggested that their son/daughter had stopped routines associated with childhood and challenged parents to treat them differently as they moved into adult life. One mother explained that her son treated her more as a carer now than the parental role she had enjoyed when he was younger:

He would have always given me a goodnight kiss, said I love you so much, he doesn't do that anymore. If I'd call him pet he wasn't happy... he would say 'I am not an animal, don't call me a pet'.

In contrast to those who still viewed their son/daughter as a child, some parents recognised their adult rights and abilities and were prepared to ease their parenting role and high levels of surveillance. This included changing the way they undertook caring roles with their son/daughter to be more respectful of their adult rights and to offer them more freedom:

In the morning it could take her ages getting ready but she hates if I interrupt... she will tell me off... so I'm trying to learn now to knock and say 'everything okay in there?'... Some of the obsessive behaviour was because she had such little control over her life... so I gave her responsibility... and that is certainly helping... She really does like her own space... I need to respect that.

Some parents also created opportunities to teach their son/daughter responsibility for daily living skills and allowed them to undertake new roles and tasks in the home:

When I am making the tea I think it will be easier if I do everything myself but I have to say no make her set the table... and she is responsible for clearing the table...

Parents also commented on the contribution their son/daughter made to their family life. For example, Robbie's mother described how much he brought a caring ethos to their family life:

Every day he will always say 'how was your day?'... He has kept the house very grounded because he doesn't cope with shouting and will say 'what is the problem here?' It actually has meant that we don't shout.



In two parent families, main carers had a particularly strong bond with their son/daughter. For example, Ronan's mother could not envisage being separated from him and reflected on their relationship:

Me and him has been here for all the years and the two of us done everything together you know... The two of us would be very close.

Similarly, Callum's mother commented on his close relationship with his father who was his main carer:

If my husband is away overnight he's asking when he's coming back and pacing up and down for hours. He can't bear not being with him...

There was a mutual aspect to this dependency as parents readily continued their caring role without expecting it to change. Indeed, some parents noted that their son/daughter undertook personal care tasks themselves at short break services but maintained an unnecessary learned dependency on them at home.

Many professionals commented on how it was difficult for young adults and parents to establish new modes of relationships in the transition to young adult life. Indeed, some key workers suggested that for more severely disabled young adults, the intensity of parenting role increased. Others recognised that during adolescence and young adult life, parents were challenged by the differing demands and wishes of their son/daughter:

It is a shock for parents. They want to go out with girls or boys and have fun, go to parties, and parents get shocked by that because prior to that they have been able to direct them... a lot of mums can't cope with it... they have cared for them in such an in-depth loving way that when they become teenagers they still want to treat them that way, they just don't know what to do.

Another key worker emphasised the importance of recognising that parents are also in transition and need support to address fears and try new services:

Parents need a lot of support and reassurance... it's a big upheaval... sometimes they can be reluctant to try things out and play down the young person's capabilities so there is a lot of work with parents at their pace...

Some professionals argued that a stepped service from school to day opportunities and more intensive work with families would help parents to shift from protective parenting approaches towards increasing self-determination for the young adult.

Planning for the Future

For a small number of families, the future was uncertain due to the health needs of their son/daughter. However, most parents indicated that they expected things to stay much the same in the future:

I never think of the future... you stop thinking of the future... you just think it will sail on like this for ever more amen...

For parents of disabled adults who were not satisfied with their current day opportunities, they were saddened by this reflection as they would prefer a better life for their son/daughter:

It will be probably the same regardless of what I would want... I would like better you know but nothing is going to change.

Parents also expressed concerns about budgetary constraints and not having access to services in the future. This was particularly the case for parents who foresaw a continued dependency on services in later adult life for their son/daughter and wanted current service arrangements to stay the same.

Professionals indicated that the expectations of parents were much higher than before with hopes for supported living and paid employment:

Parents are starting to want similar opportunities for their disabled sons and daughters as everyone else... a place of their own... they want to be here to support them with that... so they want that in place early, when their children are in their mid 20s.

However, most parents found it difficult to imagine the future and were worried that their son/daughter may not enjoy the same standards of care in the future. This was particularly the case for parents who were ageing or had experienced illness or health problems. Parents shared their worries about the future and acknowledged that they would need to make plans for their son/daughter but most preferred to delay making such plans:

I don't want to look there. I'm planning on living forever... I keep promising to adjust our will... we keep saying we are going to do it.

Professionals also commented on parents' reluctance to consider the long-term future, despite concerns about who would care for their son/daughter:

It's hard for them to accept and it's not that they haven't had that thought in their head many, many times... carers always worry what's going to happen when they are not around. But when you broach the subject, it's very hard and you just have to go very slowly and carefully and sensitively.

In most families, siblings had volunteered to be the main carer in the future. However, parents were reluctant for their other children to adopt the strain of the carer role and did not wish to constrain their own life choices. This was particularly the case for female siblings as mothers reflected on the pressures of maintaining a career and rearing a family, alongside a main carer role:

Her sister would be very insistent that she would come and live with her... but I don't think she fully understands the amount of work... I have always protected them from it because I don't want them to feel in any way obligated and I know if you have a young family it's hard enough... and she has her career... You don't want to pressurise anybody like that.



Some parents had made efforts to ensure their son/daughter would have financial provision in the future but refused professional suggestions to avail of services to alleviate pressure on their own health and prepare for the future. Others had made purposive decisions to use services such as, short breaks, to ensure arrangements were in place for the future.

Parents wanted to be involved in decisions about their son/daughter's future lives and some planned to access services in the near future when they thought their son/daughter was mature enough:

I would like him to maybe try to live on his own even if it was only a few days a week... maybe in 6 or 7 years time he would have his own independence... you know for my own peace of mind... I always have in the back of my mind if something did happen to me what would become of him.

Summary

Disabled young people's transitions to adult life can present major changes and challenges for parents to adapt their parenting/caring role and promote their son/daughter's growing independence and life choices. Parental concerns about the vulnerability of their son/daughter need to be balanced with recognition of their rights as young adults. Continuing caring roles also impact on the lives of parents who often remain responsible for many personal and daily living caring tasks for their adult son/daughter despite their own social, emotional and health needs. As a result of these roles, the relationships between parents and their disabled son/daughter were very strong. At times, this manifested in a mutual dependency with parents being reluctant to see their son/daughter move on and disabled adults continuing to rely on parents for assistance with tasks they were able to do for themselves. A major cause of concern for parents was their son/daughter's future. Families need sensitive encouragement to make plans for the future that involve their son/daughter and take steps to prepare their son/daughter for future transitions.

3.2 Post-School Options

A key aspect of the transition planning process was the consideration of post-school opportunities ranging from day care to a growing number of alternative day opportunities. This section reports on the post-school options available for the research participants, including challenges in accessing age-appropriate services to meet their diverse needs.

3.2.1 Day Care and Day Opportunities

In relation to post-school activities, two main themes emerged: firstly, the development of a greater range of day opportunities to relieve pressures on day centre provision and promote social inclusion; and secondly, the move towards specialising day centre services for those with more complex needs. With these parallel service developments, concerns were expressed about two groups of disabled young adults in transition: those who were inappropriately placed in day centres due to personal care needs; and those who were not ready to cope with mainstream day opportunities but would also be unsuitably placed in day centres.

Developing Day Opportunities

Since the first study, there had been a regional expansion of day opportunities. Practitioners, managers, parents and young adults all expressed a preference to move away from traditional day centre provision towards a greater range of age appropriate, fulfilling day activities that addressed continuing developmental needs. In the context of the modernisation of health and social care services, some Trusts had re-organised the provision of their services and staffing arrangements to focus on the development of day opportunities:

We have a huge re-investment from day care services to day opportunities over the past two years, which was a modernisation and recovery project... and it's particularly relevant at transition in young adulthood because if someone meets the criteria for day opportunities they don't go near adult centres... they take from a menu of potential day opportunities in that locality.

It was acknowledged that the development of day opportunities provided by the voluntary sector had a major impact on the diversity of activities now available. Mencap, Triangle, Cedar Foundation and Praxis Care were among other voluntary organisations mentioned by Trusts as key providers in this area and as agencies working towards more inclusive practice. However, there were also examples of statutory providers trying to develop new approaches. For example, in one Trust, a health promotion project raised disabled people's awareness of healthy living but also, importantly, raised awareness of disability issues among health professionals in the area. Such innovative projects helped to establish multi-disciplinary practice approaches and engagement with local communities. The same Trust had previously piloted a community development approach by establishing a community disability coordinator post within the community. Unfortunately, this initiative relied on this single staff member and was only funded on a short-term basis. Interestingly, however, despite the cessation of funding, three programmes established by the co-ordinator have continued, mainly with volunteer support:



There were common themes coming through that children were not able to access mainstream leisure activities... I was able to work with the parents, the young people, and local service providers and council to get things up and running... linking people to existing groups. I've been away from that post for about 3 years but three of those programmes are still running... it was good that people were able to continue with that, it benefits the children, the parents and the local community, a ripple effect...

Reflecting the growth in day opportunities, some study participants engaged in a range of activities including supported employment or training programmes and college courses. For example, throughout the week, Joanne participated in a drama based course, a college course, a training and resource centre and a part-time paid job.

However, for most young adults, access to a range of day opportunities depended on the range of options provided by Trusts and available in their geographical area. Across and within Trust areas, there was variability in provision reflecting services historically available before the re-organisation of Trusts. For example, within one Trust, in one area a strong community development approach had created a range of diverse day opportunities. However, in another geographical area within the same Trust, these services were still in need of development. One senior manager explained that variance across Trust areas was unavoidable as each Trust needed to provide services responsive to the needs and culture of the community they serve. However, Commissioners were keen to develop performance management mechanisms to ensure some parity in the type of service provision available and the development of new opportunities such as small business approaches. The integration of teams and the amalgamation of Trusts could create opportunities to learn from approaches already developed in some areas and to roll out examples of best practice to other areas. There was some evidence of this in relation to assessment approaches however opportunities for staff working across Trusts to come together and learn from each other seemed to be minimal.

In most Trusts it was also clear that control of budgets and allocation of day opportunity places was beyond the remit of the key worker and their team leader. Referrals were usually made to another team (for example, a care management team, resource panel or a community services manager) who decided whether or not the individual was eligible for a service. For example, in one Trust, the separation of roles and responsibilities meant that in cases where there were no complex needs a direct referral to day opportunities was made rather than allocation to a key worker. This division of responsibility made it difficult for key workers to secure post-school day opportunities for young people until they had officially transitioned into adult services and could be referred onwards. It also made it difficult for frontline practitioners and managers who had identified an assessed need and could not provide a service.

Parents who had high expectations for their son/daughter's post school lives were disappointed at the low level of co-ordination between child and adult services and the restricted range of post-school opportunities. They were also frustrated by professionals who tried to encourage lower expectations for their son/daughter by emphasising their inabilities or the likelihood that ambitions would not be realised. In such situations, parents often made efforts to find out more about alternative post-school options through community networks, contacts with other parents or the voluntary sector. For

example, Joanne's mother knew she was keen to gain employment and asked a local business to offer her a part-time work placement.

The In-Betweeners

There was considerable concern about some young people leaving school who were unsuitable for day centre services but also struggled with the demands of day opportunities. Most key workers highlighted that the needs of these school leavers were often not well met:

There seems to be a band of people that nearly are between day care and day opportunities... day care's not totally suitable but day opportunities are a step too far at the time... it's just about getting them ready to take the next stage because we've found that if we put them in the day opportunities programme too soon they fail and they are back in the day centre and feeling bad about themselves. If we put them in the day centre they get stuck and don't want to move on and parents like it because it is like school, it's got structure and protection.

Edel was the only young adult in the study who was not engaged in day opportunities. She remained at home because her parents felt she did not fit into either disability or mainstream services as she was more capable than peers in disability services but too vulnerable in mainstream settings where her needs may go unnoticed. Several other parents also felt that their son/daughter did not fit easily into mainstream or segregated services:

He has always seemed to have a foot in two camps. It's been very hard to pigeon hole him. So if he goes in the special needs sector he can be a bit bored and find it difficult for people to communicate with him. If he goes into the normal sector they can find him a bit boring and difficult to communicate. So it doesn't work in his favour... he gets on fairly well in both groups but never really feels he belongs in either.

These cases raise questions about the suitability of day opportunities and mainstream provision for those with less complex needs who would benefit from day activities outside the family home that are socially inclusive, whilst also being sensitive to parental concerns about their vulnerability.

In one Trust, a central 'base' was established for young adults who need a stepped approach to engage in day opportunities:

We have a base loosely attached to the adult centre... for people who are going to make that transition to day opportunities but are not quite ready for that individualised nature of day opportunities.... it's about where the person is that, if they are service dependent, if their family are anxious about them being out in the big world. The base, for a year or whatever, can be a good stepping stone... it's transitional, we don't want people to take root there.

Such a base was a service model mentioned repeatedly by staff in other Trusts who felt there was a need for a service for young adults post-school that facilitated community



participation but also provided a hub for people to come together. These respondents described an 'in-between' population of school leavers who did not fit in day centre services or day opportunities:

There is a need maybe for something in between school and adult provision ... a well-supported unit for young people who are more able and can dip in and out of day time opportunities like FE colleges and work placements but need a group setting as well, that doesn't look like day care.... with emphasis on social activities...

The provision of such a 'base' service may also help to address parental concerns about the unpredictable variance in the availability and timing of day opportunities. In particular, working parents needed reassurance that their son/daughter would be engaged in planned daily activities each day of the week for a substantial period of time. Concern was also expressed for those who were inappropriately placed in day centres because of personal care needs:

It would be lovely to have more daytime opportunities for the person who doesn't necessarily need day care but won't be accepted for day time opportunities because they need help with personal care... they end up in a group with those who are very complex... but they are very able... The fact they have somebody with them or need help with personal care shouldn't restrict them... so it would be nice if there was a service that meets people's needs who fall in between the two.

Professionals were very aware of cases often referred to as 'borderline' and the impact of being placed in inappropriate disability services on young people's self-perception.

Professionals indicated that the impact of inappropriate day opportunities on young adults could be significant, with some disengaging from services and others struggling with low self-esteem and depression. Laura's case highlights this issue clearly as she has been placed in a centre that does not meet her developmental or social needs solely because her mobility and personal care support needs could not be met in alternative day opportunities. Her key worker explained:

Her physical disability and her personal care needs is what is keeping her where she's at. I have tried to access another service but... it's the physicality of the building... so we are limited in what we can offer... It's quite frustrating.

Laura expressed her continued dislike of day care even though she had been attending the centre full-time for four years. She described feeling bored, ashamed and nervous at the centre and planned to stop attending the centre. Her comments also illustrate the impact of this placement on her sense of self:

I absolutely hate it.... I can't actually settle there... It makes me feel down... You know some days I actually come home and cry because I had got so severe... I get annoyed the minute I see that centre bus coming... I feel ashamed of going there... we do childish tasks... put things on top of things. Stick pictures on letters.

Physical and personal care needs also restricted access to social opportunities for Laura:

... last year the centre went away for one overnight and this year two overnights... we wouldn't have a mobile hoist in-house and we wouldn't have the resources to provide a hoist... but if she hadn't a physical disability she would have participated in that to the full...

Fortunately, Laura later secured a place in a local community centre which she enjoys but this is limited to one half-day per week. Laura's case illustrates the need to further develop more creative and diverse day opportunities for young adults who have personal care or mobility needs.

Even managers and providers in Trusts that had developed creative alternative day opportunities felt that these were often small scale and time limited due to short-term funding arrangements. Indeed, during the course of the study a training and employment opportunity that was described as excellent by service users, parents and key workers failed to secure continued Trust funding and closed down. One respondent also commented on the impact of funding streams and restricted, inflexible access to alternative day opportunities:

There are a lot of people misplaced, not just in statutory day care but also in the alternative programmes to day care... they were pigeonholed there. Some of it is blinkered worries about double-funding, for example if someone is in a Trust run day activities programme they wouldn't also be in a supported employment service and college but if you want to live a full life you should be able to access all of that and change if people don't have a good experience.

In addition, when limited places in day opportunities were filled it was difficult to create new capacity within the system:

People tend to go to day opportunities and nobody ever moves they on and that becomes clogged up...

Across Trusts key workers expressed a need for the further development of a greater range of day opportunities that would allow young adults to change services and progress to new activities:

There are very limited opportunities... You have limited college courses... or you have the training for work programmes... really the options are limited.

Likewise, social care managers suggested that with increasing demand for alternatives to day care from a younger population, further investment and growth in day opportunities across sectors is required:

We would like to see a greater mixed economy of more day opportunities.... Those with a higher ability are looking for a greater menu of services. We need investment to help us grow this area. We also need other government



bodies, education, social development, employment and learning to come to the table to create the opportunities... the whole system needs to join up.

Day Centre Provision

Whilst there was a clear focus on developing alternative day opportunities in each Trust, most professionals confirmed that day centres are still the main option for those with more severe levels of impairment or high levels of personal care needs. Indeed, half of the participants involved in this study had transitioned into a day centre-based service for at least part of their week. These young adults had mixed experiences of day centre services. Some young adults accessed a range of professional support and activities at day centres, such as, physiotherapy, leisure opportunities, drama and further training. Sarah's mother also emphasised that the day centre provided the same routines and levels of care that she received in school. Ronan also enjoyed the routine of the centre and the opportunity to meet friends there:

We go to town, look around shops and go back, get our dinner and then it's time to read the papers. And we have a meeting sometimes... talk about news... You would see your friends in it and say hello to the staff... Fridays we do dancing...

Interestingly, Ronan expressed a preference to attend the centre for a full week rather than going to college on some days because he could take things easy there. The lack of challenging or new learning opportunities at the centre was noted by his mother who encouraged him to continue with college attendance:

For learning things he would be better having his two days to the tech... the centre is great but... more or less they just do their own thing.

Similarly, those who disliked day care indicated that the activities were aimed at people with lower levels of ability and did not encourage them to reach their potential. This was often due to service users' mix of ages, needs and abilities. Some providers made efforts to group people of a similar age together however the age range of attendees did vary.

Some managers indicated that further service development is needed to avoid a traditional reliance on day centre provision at the stage of transition from school. The re-settlement agenda had also led day care services to focus more on services for those with more complex and challenging needs. Indeed, this increase in the number of people with challenging and complex needs entering day centres had created difficulties for some existing service users, with two study participants ceasing centre attendance due to the changing service user profile.

The demand for day care places was a significant concern for most Trusts with some service users experiencing significant delays or gaps in service provision:

There isn't capacity within day centres for people with a profound level of disability... It can be frustrating when key workers see the need and the person is left without service and are still at home because of the capacity issue... if we don't move people in transition straight into daytime opportunities... we are not going to be able to meet the very high complexity and high dependency needs coming through.

These issues were clearly evident in Sarah's case. Although her transition plan clearly specified a need for a day centre place due to her intensive support and supervision needs, she spent almost a year at home with her parent before eventually securing a part-time day care placement. With many day centres at full capacity, there were serious concerns about how young people due to transition from school will be able to access these services.

Summary

There has been a positive shift from an over-reliance on traditional day centre provision to day opportunities. However, there is still a need to further develop the range of day opportunities available across the region and to monitor outcomes for young disabled adults. There are concerns about groups of disabled school leavers who are falling between the gaps in services. In particular, those who are not suitable for day centre services but do not yet have the skills or confidence to engage in alternative day opportunities. Several respondents indicated a need for a 'base' for these young adults to ensure they are supported to engage in day opportunities rather than becoming stuck in inappropriate services or remaining at home with no social outlets. There is also a gap in day opportunities for young people who have personal, health or mobility related care needs. There is concern that these young people are being inappropriately placed in day centres for those with more complex needs.

3.2.2 College and Further Education

Seven of the young adult participants had accessed college courses on leaving school. While some described feeling very happy at college, others felt unsupported and struggled during their early days at college. For example, Lorraine began a course at a college some distance from her family home but ceased attendance after a few months because she was not coping with the course content and the lack of familiarity with the area. Several professionals also highlighted the importance of providing adequate supports for disabled young people following the transition from school to college:

Some of the young people have left schools with a very high level of classroom assistance and they're not replicating that environment in the college, and it causes emotional problems for them. They get very anxious or they can't follow the boundaries and it breaks down... it's just too overwhelming.

In most cases, participants were studying general life skills, computing or employability courses. Most participants attending college did not know what course they would study from one year to the next and often repeated courses they had previously completed or that did not stimulate any further learning. For example, Joanne was studying a basic computer course despite having completed a more advanced course



previously. Unfortunately, college courses were often repeated with no planned progression into employment. The most striking example of this was Ronan who had been attending the same college courses for ten years which had not led to any recognised qualifications or work experience. Interestingly, although he had a part-time job since he was 16 years old, no efforts were made to draw links between this work experience and his college studies. Ronan's experience was by no means unique as professionals also reflected the same issues for other young adults on their caseloads:

You get people with a learning disability going through training and re-training and re-training and as a principle it is totally wrong but... there are people who have been here for 10 years and they have their mates and they have their routine, change is difficult... There is a community of people that go to college.

For young adults repeating the same courses, attendance at college was perceived to be a more attractive alternative to being at home or attending a day centre. As such, college was often viewed as an alternative care placement or social outlet rather than an opportunity for further education, learning or progression to employment. For example, Ronan expressed a desire to leave college but his mother explained why she was keen for him to continue with his attendance:

He started saying he didn't want to go back... and I said he doesn't have anywhere else to go... it is two days that he has nothing to do, you know he is totally lost.

Professionals also indicated that students often repeated the same courses they had undertaken already at school. Professionals and families expressed a preference for inclusive and stimulating learning opportunities at college however, available provision was limited:

There's a lot of repetition... there are a lot of people that learn and go nowhere... and that is about studying what is available rather than what they want to do. I don't think that the colleges are developing opportunities...

Some professionals were concerned that level one college course options had become more limited as there was a stronger focus on higher level academic studies. Unsurprisingly, given the lack of progression and restricted course options, colleges were reporting a lack of available places.

College did provide opportunities to spend time away from family however, young adults were usually in classes with other disabled people rather than being included into the mainstream culture of the college, as a transition co-ordinator noted:

There is a real opportunity to promote social inclusion in college but again they are very segregated within their group and not integrated.

Interestingly, some parents were pleased that there were segregated options at college and special provision to address the vulnerability of disabled students.

For most participants attending college, it was the main opportunity for social interaction with peers their own age and they were often in classes with other young people who had attended their school. Only one young adult commented on being in a class with older people and not having social contacts in college. In some cases, college provided an opportunity to spend time in the local community at break times and to form personal relationships. When asked about the good aspects of college, young adults most commonly referred to spending time with friends. Ronan was in the same class at college as a girl who had attended his school and they had formed a close personal relationship. They went to lunch together and kept in contact by telephone outside of college hours. Similarly, Maurice disliked his first year at college and planned to leave as soon as possible however when he started a new course the following year he described his week at college as 'amazing' because he had the opportunity to mix with a new group of peers and potential girlfriends.

Ironically, although college presented some new social opportunities for young adults it could also be a place where they experienced discrimination and abuse. Several participants described experiences of being taunted or 'pushed' by non-disabled peers at college. These findings have implications for how well colleges support social inclusion and interaction with non-disabled peers as these students were attending specialist courses and were not integrated into the mainstream life of the college. Colleges could implement strategies to address disablism by raising disability awareness and promoting opportunities for social inclusion.

College courses that were linked to training for employment or work experience were the most relevant and successful further education opportunities. For example, Natalie was very satisfied with her training programme involving two days of work experience and one day of study. Young people and parents also found it helpful when schools facilitated attendance at college courses in preparation for transition from school. This helped to familiarise young people with the college setting and decrease parental anxiety about moving to a new learning environment. However, given these early links with schools, more efforts could be made to ensure post-school courses at college are not repetitive of studies already undertaken.

Summary

There was concern about limited level one and two college course options and, as a result, students repeating the same courses over several years with low expectations for further progression. Respondents indicated that careers advice for school leavers could be developed including stronger links with employers in the local community and person-centred course planning that avoids duplication and course repetition. Monitoring educational outcomes and progression is crucial to ensure progress through further education and training opportunities. Person-centred transition planning should be continued into young adult life to support further transitions and encourage disabled young adults to reach their full potential.



College based courses were most commonly segregated. Whilst some young adults were able to form social or personal relationships, these were often not maintained outside the college environment. Schools and colleges are well placed to offer increased opportunities for social inclusion and to promote skills for forming and maintaining social networks of support.

3.2.3 Supported Training and Employment

Regardless of post-school placements, most young adult participants wanted to fulfil ambitions to gain employment. Four out of the ten young adults had accessed training and employment opportunities. Two of these young adults were still engaged in training so it was not possible to judge whether or not they will lead to paid employment. These young adults were enjoying the social and training aspects of their programmes:

I like to be working... I work hard... it's for training for work... I have friends there. It is really good...

Natalie and her mother were very satisfied with the training and employment agency that supported her as they identified new work experience when initial placements were unsuccessful and remained committed to their support role even as their service was closed down due to budgetary cuts. Her mother explained:

The first two placements didn't work out... so then they got her into this training programme... and it's brilliant. They sorted Natalie out whenever they were closing down and they didn't have to because they have lost their jobs now but they did do it... right to the very last.

Providing continued support during the early stages of employment was important to avoid placement breakdown.

Robbie's parents were hopeful that their son would move into paid employment but encountered low expectations from professionals who advised this was unlikely:

We brought up paid employment and they seemed quite taken back... I feel that nobody else would be expected to work for nothing, why should they? I was taken back when the social worker said to me, 'Would they have him if they had to pay him? Would they need him or would they employ somebody else?' I didn't find that very encouraging or pleasant.

Reflecting this experience, some professionals demonstrated low expectations and emphasised the importance of support for disabled people:

We need to be realistic and look at the potential of any young person to be able to work... should it be some work, some recreation, some contact with peer groups? I wonder about the expectations that are being created... they say, we will get you a pathway to employment but realistically, in all the years that I have worked here, one person who has come off benefits... and

unfortunately he has actually lost the job... actually are their needs better met within supported services like our day opportunities?

Most parents had a realistic understanding of their son/daughter's abilities and, in some cases, when they were presented with limited options or low expectations, parents sought out employment opportunities for their son/daughter themselves. This was the experience of Joanne, as her mother secured her part-time position in a local hairdressing salon. Joanne explained how she enjoyed this job:

I wanted to get a job and I got one. Though I did get a work experience first... I work part-time at the hairdressers... I really like it... because they pay me and that's better.

Likewise, Lorraine had progressed from training placements into a part-time paid position in a local supermarket. Lorraine felt a sense of achievement at having secured paid employment:

I wanted to go for it... I applied for it over the computer with X [support worker]. With the thousands that applied 19 got through for the interview and only 7 made it... they told me in interview that I got it...

However, her mother explained that she had experienced previous unsupportive work placements and emphasised the importance of flexible work arrangements and a positive workplace culture that was willing to meet the individual needs of employees:

She was in a wee shop before that and she was falsely accused of stealing... she then went to work in a clothes store and fell out with the boss and walked out and they didn't even tell us... and then they got her into the supermarket as a volunteer and that has made a great difference to her life. They have been fantastic... their work policy is very good they look after each other... they knew her abilities.... There were no big rows, it was 'we can work with you'... In the other shop, they changed her days of working without telling her...and she couldn't cope. In this job her manager was prepared to talk to her and treat her as a person and it works fantastic.

Lorraine also emphasised the importance of having managers and colleagues who understood her needs and manageable working hours. Likewise, Joanne preferred to keep her current range of day opportunities and only work one day per week in the hairdressing salon. This is an important finding because some other young adults were discouraged from pursuing employment due to concerns about ability to sustain employment due to fatigue or additional needs.

Professionals reported a dual need to help employers understand disabled employee's abilities whilst also teaching young adults an essential work ethic. This was partly the reason why professionals noted that families seemed to prefer programmes that offered work placements alongside college-based learning to ensure necessary skills were developed and work was appropriately paced.

Two participants enjoyed short-term work placements. Maurice described his short-term placements as 'extremely amazing'. However, these were time limited and did



not provide any opportunities to progress into further work experience. This was frustrating for these young adults who aspired to move into paid employment:

I had a job... I did try to work and I loved it... but it only lasted 2 ½ weeks.

Young adults who were keen to move into supported or paid employment were unsure if they would have the opportunity to achieve this goal and lacked information about who could provide support for them. Some were concerned that they would not be able to secure employment because of low expectations or lack of qualifications, as Laura explained:

They put a label on you as disabled... ‘Oh you can’t go away for a job because of that’... I want to be in my own wee job on the go all day... I know if I was interviewed to get a proper job they wouldn’t take me because I haven’t got any GCSEs.

Parents also often had reservations about their move into supported employment. Maurice’s mother felt he needed more experience of varied work environments and intensive training to develop the skills necessary for employment. She also emphasised that support workers need to have a realistic understanding of his abilities to ensure work experience and support is tailored to his individual needs. Likewise, Laura’s mother explained that she was severely restricted in choices of work experience due to her mobility and personal care needs. As a result, she felt that staff at the training and employment programme had unrealistically raised her expectations of future employment:

I was a bit annoyed with them because they had them all thinking we are getting a job... I said ‘what kind of job are you going to give her?... in an ideal world I would love Laura to be out working. They said there is a great job that would suit her but unfortunately it’s filled... and that was the only job she would get into so I thought what a waste of time and having these kids all hyped up about getting them jobs and it’s never going to happen...

Several parents reported that work experience was not a likely option for their son/daughter due to their particular support needs or a concern for their vulnerability and safety. The influence of parents and families who are concerned about care and protection cannot be underestimated. One respondent from the voluntary sector suggested that one way to raise awareness of the working potential of disabled young adults and change traditional mindsets is to highlight success stories:

The more people who are in paid jobs, the more examples families and employers and school see... seeing people doing better raises the bar.

These findings suggest a need to examine the diversity of supported work placements and extent of supported employment initiatives for those who may require more intensive support but are capable and interested in employment opportunities. There is also a need to provide more information directly to young adults and their parents about supported training and employment opportunities available, from a balanced perspective that promotes their rights and abilities whilst also ensuring goals are realistic and achievable. Raising awareness of success stories and peer mentoring may

also help to redress lower expectations for learning disabled adults to progress into employment.

The Benefit Trap

Many professionals referred to the 'benefit trap' as a barrier to moving into paid employment. Several young adults had expressed a preference to keep part-time hours that would not affect their benefits however others were keen to pursue full-time paid employment. Professionals indicated that some young people and their families worry about moving into the uncertain world of work which may not be successful and losing their benefit income.

The biggest drawback is the benefit system as parents don't want this young person to lose their benefits... It's not that people are deliberately taking advantage, it is just how people's lives have got into that mindset... the right to disability benefits as opposed to getting that opportunity to be working... 'you will hold our hands until they get out there but there is no-one to help if they fall down, and how are we going to get back into the benefit system?'

Several respondents also referred to the impact of the current recession on opportunities for disabled people to access paid employment:

We have a lot of people in employment to the extent that their benefits allow... our clients aren't terribly well placed to compete in the labour market... in a second recession there aren't many jobs so employers are looking for the most they can get out of any situation.

Some respondents also referred to a lack of understanding among employers and potential discrimination, reflecting disablist public attitudes:

The first thing is how productive will the individual be because at the end of the day it is a business... when it comes to placements that break down it's because the individual couldn't cope with it or they weren't productive enough... I understand if you are running a business you can't be caretaking as well and for a lot of our people, that's what they need... there is room for education for all of us about where people with learning disabilities fit into the world, where are we going as a society with this.

Within this context, there is a shift back to unpaid voluntary work experience which keeps the young adult in work experience and visible in their local community. Two study participants were in this position of working for a few hours each week in a local supermarket, mainly stacking shelves. Ronan started this work when he left school and it had continued since then. He liked this experience of work, particularly because it gave him the opportunity to engage with members of the local community. However, there was no opportunity to further develop his role or progress into paid employment. Similarly, Robbie's mother felt that his work experience could be further extended to allow him to develop new skills:



All he is doing is stacking the shelf... if they were paying him they would have to put in more time showing him a lot more to do and training him up and keeping an eye on him, whereas now he is left to his own devices.

One voluntary sector provider explained that funders are more concerned about numbers participating in a service instead of meaningful employment outcomes:

The focus is on numbers of people using the service, how long on a waiting list, numbers of enquiries... They are less interested in progression, as long as you are working with them.... We need to get better at monitoring people after they leave us, how many are in paid employment?

Several managers also commented on the need for more collaborative engagements between sectors with the full range of providers taking responsibility for the employment support needs of young disabled adults.

Summary

Most young adult participants were keen to pursue employment in the future. Two young adults had secured part-time paid positions and several others were in training for employment. However, professionals and some parents had lower expectations for employment due to concerns about vulnerability, the competitive labour market and loss of social security benefits. Short-term work placements were valued by participants but did not usually lead to longer-term progression into employment.

Findings suggest a need to: monitor the employment outcomes for disabled young people engaged in work placement or training opportunities; and explore the diversity of work placement options available to challenge young disabled adults to learn employability skills in a supportive environment. Success stories from employers of disabled young people and those in employment would help to share good practice and raise awareness of the possibility of moving into employment and types of support and work culture that lead to successful employment outcomes.

3.3 Disability, Identity and Social Exclusion

The section explores young adult perceptions of disability, impairment and self-identity which were often related to post-school experiences and linked to use of services. Opportunities for social inclusion and developing relationships are also addressed, alongside consideration of the dynamic interplay between rights and perceived vulnerability and risks.

3.3.1 Disability and Identity

When asked to describe themselves, most participants referred to their age, appearance, personality or family. These descriptions were mainly positive and not related to impairment or disability. For example, Natalie described herself as funny, caring and kind. Others referred to their hobbies and interests including reading, writing and cooking.

A couple of participants reflected on how their personalities had changed positively over the years, particularly in relation to social participation:

I'm more active now than I was when I was little. I like to shop, I have a job. I'm very friendly and outgoing.

When I was younger I never headed out. That's one thing I would change so I would probably have more friends now of my own... and more confident about myself... I should have headed out more when I was younger but I just acted like a wee weirdo in the corner, just afraid of going out. I was shy...

In the second study, participants engaged in more discussion of their experience of impairment or 'feeling different'. For example, participants could name their particular condition or explained different impairment effects. However, most participants were still unsure about their own impairment. They could discuss the impact of impairment effects (such as, not being able to walk) or disabling experiences (such as, bullying or inaccessible places) but had still not been given accurate information about their own impairment. For example, Joanne knew she had a learning disability but was not quite sure what being disabled meant:

I am disabled... I am learning disabled... I don't know what that means

Laura was aware she has a physical impairment but was uncertain about learning disability. Her response is interesting as she has been receiving services from the learning disability teams for most of her life.

My left side isn't working properly and I am brain damaged. My legs don't go the way my brain does... What is a learning disability?

***I: Some people with a learning disability might find it harder to learn or need more time to learn new things
Would you say I had that?***



*I: I don't know. Would you say you had it?
No. I definitely have physical disability.*

Interestingly, some participants viewed impairment as a positive or unremarkable aspect of their identity. For example, Edel explained how impairment impacted on her learning but was just part of who she was:

I had problems spelling and like reading and that. It's awkward but it's like you are who you are and no-one is perfect in this life.

A few participants suggested that the effects of their impairment lessened as they grew older, as Natalie explained:

*It doesn't really affect me that much now because I have grown out of it...
Just sometimes I find it hard to read and write and say words properly...
I'm better than I was.*

These changing impairment effects may reflect a move from the school environment to other settings with less focus on education and learning.

Access to Information about Disability or Impairment

Parents adopted different approaches to informing their son/daughter about impairment. Some parents briefly mentioned it whilst others chose not to inform their son/daughter due to concerns about the impact on their self-esteem. Sharing information about impairment was often described as a difficult issue as parents were unsure how much information to impart or how to explain impairment to their son/daughter. Some parents believed their son/daughter had very limited understanding and would not be able to comprehend concepts of impairment or disability. In cases where impairment could go unrecognised, parents were often torn between a reluctance to impose the category of disability and a concern that others have unrealistic expectations about their son/daughter's ability. For example, Edel's parents avoided using the term disability and did not allow her to avail of disability-related services that would categorise her as disabled:

Because she thinks she's well we did not want to put her into that situation so we kept her at home... I don't think it would have done very much for how she felt about herself you know.

Other parents felt that their son/daughter identified with being disabled and had some understanding of their impairment. In particular, participants who required assistance with personal care or used specialist equipment were acutely aware of their impairment-related needs. Laura used a wheelchair user and required a high level of assistance with personal care. The use of specialist equipment was a key issue for her as it had both positive and negative effects on her life. The extract below is part of a reflection she wrote for her secondary school describing the positive impact of a new power wheelchair on her life:

I feel like I've got my own legs back because I don't feel like I'm just sitting in one place anymore. I can help my mum to put away the shopping and set the table. I can answer the phone and at school I can give out the children's

breaks. I used to get depressed when I had my old chair but now it's made such a difference and feel like I'm a useful person and I'm much happier.

However, Laura was very reluctant to use any additional specialist equipment. At the time of the second study, her occupational therapist was planning to provide additional equipment to assist with toileting following a recent fall in the home. Laura was adamant that she did not want any additional equipment to be installed and viewed use of specialist equipment as a negative effect of having an impairment:

I think disability's horrible... because if I didn't have one I wouldn't have the OT telling me what I can and can't have... I don't like when you have to have toilet chairs when you don't like them.

Later when asked about what she would like to change about her life, Laura listed all of the specialist equipment and services she used:

I wish that I didn't have a chair. The hoist in my room... The bath and toilet in my room... the fact that carers have to come in.

Laura's views suggest that whilst specialist equipment can sometimes be positively life changing, other equipment can emphasise limitations and negatively impact on self-identity. In a later discussion about how Laura would describe herself to someone new, she explained that she would prefer not to disclose that she uses a wheelchair because of negative assumptions people may have about her:

I: And would you tell them that you use a wheelchair?

Probably not. Not until they first saw me... I would be quite scared of what they thought

I: What do you think other people might think?

Oh she can't get off her backside and work

As young people moved into young adult life, they sometimes became more aware of the pressures of caring on their parents which impacted on their sense of feeling like a burden, as Laura's mother explained:

She did go through a phase 'I wish I could walk' or just stand up and it was tough... she does notice it is difficult... everybody is involved pulling and hacking, you have to take two ramps so she is aware that it is not easy... she is always saying 'sorry mummy you shouldn't have to do this'.

Other parents explained that their son/daughter gained knowledge of impairment and disability from participation in disability-related services or activities. Indeed, in some cases, parents indicated that their son/daughter chose to associate with being disabled to help explain their behaviour or access new social activities. For example, Callum's mother did not believe he understood what autism meant but he used his diagnosis of autism to explain why he finds it difficult to tolerate other people's behaviour:

If he is in the bad temper or... if there is somebody who is annoying him and I would say 'You have to respect that she has autism' and he would say



'But I have autism too and no-one respects me and my feelings'. So he uses it sometimes or if you are getting onto him he says 'Don't you know I'm autistic?'

It is important to note that some parents also lacked information about impairment. For example, despite years of concern about Ronan's health and development, his impairment was not diagnosed until he was twelve years old. Seventeen years later, Ronan's mother still felt she did not have clear information about his diagnosis. In addition, some parents felt their son/daughter's impairment may have changed as they moved through adolescence into young adult life. Callum's mother explained that as his level of ability had changed they were unsure about his diagnosis despite a recent psychological assessment:

The psychologist said he had done quite well on the IQ test and she was very surprised... so I'm not sure if she thinks he has autism or not it's hard to know... He has changed quite a bit, he's far more sociable.

This lack of information or confirmation of both impairment and ability limits the level of information parents can share with their son/daughter. It is also likely to have a major impact on parental decisions affecting their son/daughter's adult lives and may lead some parents to unnecessarily restrict or exclude their son/daughter from opportunities due to uninformed concerns about risk. This finding highlights the importance of continual access to information and opportunities for re-assessment as young people develop and transition into young adult life.

Feeling Different and Being Treated Differently

It was clear in the second study that as participants had grown up they had compared themselves with disabled and non-disabled peers. Based on these comparisons, participants had mixed views on impairment and disability. When young adults accessed life opportunities that matched their expectations or that mirrored the lives of their peers or siblings (for example, attending college or engaging in further training and employment placements) disability was often not a major issue. For some participants impairment was a unique personal characteristic. Joanne explained that everyone was different and disability did not really affect her:

I am learning disabled... It doesn't affect me one bit... I do need help sometimes to spell sometimes. I can't spell very well. It's alright... because all people are different

I: Do you like being a bit different?
I do yes

Joanne had limited knowledge of various impairments but she explained that disabled people are just like anyone else:

We are all different. People can have spina bifida but I don't know what that means... I think be all brain damaged... I have Down's Syndrome

I: And what does that mean?
I don't know

I: And how do you think other people treat people with Down's Syndrome? The same. Like any normal person... I do have Down's Syndrome or a learning disability but I am still normal. I do normal things. People with Down's Syndrome or learning disability like I have can do normal things.

Likewise, Ronan highlighted that he was different on the basis of unemployment and inability to drive:

Not people like me... I don't drive. I don't go out and work on a building site.

His mother explained that he felt different from his non-disabled peers and siblings and was often frustrated about being treated differently which leads to challenging situations within the home:

He would know that he's a bit different... The situation of going out, not getting out on his own... at times like that he would get frustrated and very angry... two years ago he totally refused to take his medication... and wasn't sleeping at night. He was completely hyper and then he broke my ribs...

Ronan's mother struggled with her decision to protect him by excluding him from social opportunities other family members enjoyed:

He keeps saying to me why can he not go out at night on his own... when his siblings are all going out he would want to go with them. He would say to me 'Sure I'm the same as the rest of them. I'm not different from them you know'... I do feel I would like him to go somewhere like that with his own age group but unless you have someone you are sure is going to look after him and you can't trust nobody. God knows if anything happened him... It's hard you know... he is 29 now and when I was 29 I was married... but you have to say 'You can't go' at the end of the day.

Laura's mother also noted the negative impact of impairment and personal care needs on her social opportunities in comparison to her non-disabled siblings:

It's hard to see the other two going out and she is being put to bed. You know and they are only going out... She never mentions it, she just seems to accept she wouldn't.

Being treated differently was a central theme in the interviews with young adults. Laura was particularly annoyed when other people judged her to be less able because she uses a wheelchair. Similarly, although Joanne did not view impairment negatively, when she interacted with others who treated her differently, she felt annoyed:

People don't listen. People don't understand what people who have Down's Syndrome like me are saying. People can't make out a word you're saying. Sometimes I find it very annoying... I don't like that... in college one day I wanted a book out and they didn't listen... it's very annoying...



Edel also commented on how other people discriminated against disabled people:

It's really sad when people are disabled and people just laugh at them anyway but they're born that way. It's like what makes you so perfect. You should really get to know them before you judge. They were born that way, so just back off and live your own life and stop being such a sado.

As a result, some participants disassociated themselves from disability or disability services. For example, Laura felt that the day centre's predominant focus on impairment made her feel more disabled, devalued and patronised. Activities at the centre were pitched at the level of other more severely disabled and older service users which Laura did not enjoy. However, she had a different attitude to the community centre she attended where she felt included and valued, participating in more interesting activities. The community centre service was also a segregated service for disabled people, some of whom use specialist equipment, however, Laura perceived its approach and the environment to be more empowering:

I feel very happy there. It's not all about wheelchairs and disability. They don't talk about disability there... We all are disabled but you wouldn't notice it.

Emotional Wellbeing

The emotional wellbeing of young adult participants was a key issue. Laura explained how her realisation that she was disabled as a teenager impacted on her emotionally:

I saw people looking at me funny... when I was younger I didn't care... It was when I hit 13 or 16. Mum will tell you I used to lie in my bed and cry.

In a later discussion, Laura explains how it still impacts on her physically and emotionally:

I feel sad that I can't do things. I get down sometimes. Like my sisters and cousins going to stay in a hotel. I can't go. I will be depressed when they go and I can't go... My chair holds me back.

Four participants experienced high anxiety levels and panic attacks. Another four had been diagnosed with depression, including one participant who had self-harmed. These four young adults were all taking anti-depressant medication. Callum's mother explained how he had developed high anxiety levels:

He was very down and he would have cried a lot for no reason... so he was obviously a bit depressed so he was put on anti-depressants and then, he has terrible anxiety... it just kind of took over so he's on medication for that too.

These findings highlight the importance of emotional support for disabled teenagers, addressing issues of identity and self-confidence and early intervention to anxieties and depression.

Interestingly, a few young adults reported positive opportunities they had for peer support and sharing life experiences with other disabled young people. For example, Lorraine explained how she shared experiences of hospital visits and scans with a friend:

We were discussing what head scans we had because my friend was going for one after she had a seizure. You know they keep you awake for that and she was going 'they didn't say nothing to me about staying awake' and I go 'they did it to me, they keep you awake and ask you who the president is' and I'm going 'I don't know who the president is'! We were discussing the ones that were more uncomfortable and I said 'don't be scared about the noise in the one where you lie down and it takes you in'.

Natalie also emphasised the importance of supporting other disabled young people:

I know some of my friends have disabilities... it would be hard for them and I just help them really to understand what a disability is and different things so I can help them and they can help me get through things.

The important impact of such mutual peer support on promoting self-confidence and understanding experiences of impairment and disability is a key area that could be further explored by service providers.

Professional Perspectives on Disability and Identity

Some professionals were sensitive to how young adults constructed identities on the basis of how others saw them and the potential for internalised oppression:

A lot of the young adults have big identity issues in terms of how others see them... there is a lot of making sense of who you are and sometimes negative messages that can be internalised.

These issues are particularly relevant for young people in the transition to young adult life who may or may not be exposed to positive messages about disability throughout their lives:

The psychological issues that young people face as they move into adulthood become more real for them... they have greater issues in regards to their self-esteem. Sometimes it is down to how parents are told about the disability to start with and how if you keep the message positive and about opportunities.

Most professionals emphasised the critical role of families in terms of their view of disability and their attitude towards promoting inclusive opportunities for their child.

There was a lack of clarity about who has responsibility to meet the needs of young adults who are experiencing depression or self-harming behaviours. Many key workers suggested they would refer to psychology, psychiatry or behavioural teams. However, a few social workers indicated that social work should play a significant role, in recognition of their professional expertise and their relationship with the young adult:



In reality it would be a referral on but the disappointing thing is that those staff would be therapeutically trained. A social worker is not an admin clerk who goes out to someone's house and pulls out a load of forms but that is some of the reality... The traditional social work role is being lost... staff are finding that very difficult because... they are not using their social work skill set.

There was a general consensus among professionals that many disabled young people had little knowledge of disability rights or social model ideas. Although some voluntary organisations had established services aimed at building awareness of the human rights of disabled young people, how well those efforts impacted on the experiences of young, learning disabled people was questionable, particularly given the strong influence of their environment, service labels and family attitudes.

The other thing you have to counter is the message that young people with a learning disability get from quite an early age, from 12 or 13, you can't do that, you can't take part in that, that is not for you, you are not able, the problem is with me. You can see that in their self-esteem and identity... you have to fit into the service, you have to fit into the school rather than the school changing the way they teach... Even in adult services, people feel they have to go to day centre... they don't know much more than that's there.

Summary

Young disabled people making the transition from teenage years to young adult life are at a life stage where experiences of impairment and disability can impact on their construction of self-identity. Enabling attitudes and approaches from family members, peers, advocates and professionals can help to buffer disabling experiences and support young adults to develop positive self-esteem. However, lack of access to information about impairment and disability rights, inappropriate post-school placements and limited opportunities for peer support can negatively impact on the emotional wellbeing of disabled young adults. Social workers could play a greater role in meeting the emotional, identity-related needs of disabled young people in transition as they should have an established person-centred, key worker relationship.

3.3.2 Social Exclusion

A major theme in the first study that was still a persistent issue in young adult life was the absence of meaningful and sustained social relationships. Many professionals highlighted social inclusion as a core area for further development and emphasised that a cross-sector approach and societal change was required to address social exclusion:

We still are behind in terms of inclusion, a lot of the young adults have difficulty accessing mainstream social and leisure activities... very few are experiencing inclusion in their local communities and using mainstream services... that is a fundamental part of transition... it cries out for cross-departmental working... it is about the responsibility of organisations to include and provide the access and support required... and it is society's responsibility.

Similarly, parents were concerned about their son/daughter's lack of meaningful friendships and opportunities to socialise with their peers:

She doesn't have friends that she would go out with... that seems to be her biggest stumbling block... and that would worry me... I always think you need a friend to talk to.

In the first study, most participants had formed social networks at school. However, by the time of the second study, participants had left school and these friendships had ceased. Only one young adult was still in contact irregularly with school friends. This was often due to the fact that disabled young people attended segregated schools or special units in mainstream schools with classmates who were not from their local community. When school ended, so did their contact with this social network.

In the second study, none of the participants had friends who visited them regularly at home or socialised with them routinely outside of service settings. Natalie was the only participant who had a very close friend and they spoke daily on the phone. Most participants described having friends at their day centre, place of work or college. This is an important finding as it highlights the important role of further education and training service providers in facilitating and encouraging social relationships for young, disabled adults. However, these social contacts always ceased when they left these service settings and rarely crossed the boundaries into the personal social lives of the participants. This was most notable during the summer months when day centres and colleges were closed and young adults had few or no social outlets. In addition, many participants did not have social outlets or activities at weekends.

Occasionally, participants had re-established previous social contacts from school at colleges or day centres. Again these re-connections were mostly restricted to those service settings, apart from Ronan who formed a relationship with someone he knew previously from school and they kept in touch at college or by phone.

Participants who were engaged in social and leisure opportunities were heavily supported by their parents and often only accessed provision for disabled people such as, the Gateway club or Special Olympics programme. Parents reflected on the lack of inclusive, mainstream social opportunities:

His whole social life is all centred around disabled groups, anything he ever does... if we don't put the effort in and take him he would just be sitting in the house all the time... We find that the hardest... there is never anybody coming to the door for him.



For some participants, such segregated spaces provided a much needed safe, social outlet to meet other people of a similar age with impairment experience. In the absence of inclusive mainstream social opportunities and peer advocacy services, these opportunities to spend time with peers were an important social experience.

Over the years most parents had made efforts to assist their son/daughter to develop social networks and friendships by encouraging them to interact with peers, arranging social activities with peers, and supporting them to participate in social clubs. In many cases, friendships established in this way were short-term and reliant on the continued effort of parents. By the time of the second study, some parents seemed to have accepted that developing friendships was not a priority for their son/daughter or they did not have an understanding of the concept of friendship. Others still made great efforts to facilitate their engagement in social and leisure opportunities. These parents transported their son/daughter to social activities, stayed to supervise or support them and made concerted efforts to help them develop social relationships.

Three participants had access to befriender services or domiciliary support which facilitated participation in social activities outside the home without parental involvement and at weekends, for example, going to the cinema or shopping. Some participants referred to carers or bfrienders as friends and some parents reported that this level of friendship satisfied their social needs. Some participants found it difficult to socialise with their peers as they had different approaches to social engagement and varied social skills. Indeed, some reported that other people annoyed them or they were concerned for their own safety when mixing with disabled people presenting with challenging behaviours.

Interestingly, a key social activity for most participants at home was use of the internet. This was one of the main changes since the first study, as participants had developed their IT skills and use of online social media sites had expanded. Some participants spent time online viewing and searching for cartoons, music, lyrics and movie clips. Others used social networking sites such as facebook to engage with social contacts or extended family. Some parents restricted the time their son/daughter was allowed to spend on the internet. Parents also had reservations about their son/daughter's use of social media sites. Parents or siblings usually covertly supervised online social activity, often in response to concerning online communication or situations that had upset their son/daughter. For example, Edel's mother helped her to block contact with someone who had been pressurising her for money online and restricted her online social contacts to family members only. Likewise, Natalie explained why she stopped using facebook:

I did use facebook for a while but I don't have it anymore... I just got too addicted to it and so many people were online and I really didn't know what to say them and people were annoying me on it too.

Five participants described enjoying opportunities to participate in community activities. Ronan often spent time in his local area engaging with neighbours and emphasised the importance of keeping up-to-date with local events and people. He was well informed about local football fixtures and results and used this knowledge as a topic of conversation with local people. Participation in the local football community was also an important social outlet for Robbie who supported his local team and showed the researcher photographs of him with the winning team. Other participants enjoyed

feeling a sense of social and community inclusion when they played key roles in the family or at family events. For example, being responsible for the weekly grocery shop, cooking a family meal, helping to organise extended family events or being a member of a family wedding party. Several young adults also participated in fundraising events for local charities. All of these activities provided important opportunities to engage in mainstream experiences and to feel a sense of contribution to their families and local community.

Experiences of Bullying or Abuse

Half of the participants in the study had direct experiences of feeling unsafe socially as a result of bullying or abuse. Of the remaining five participants who did not disclose experiences of bullying or abuse, three did not take part in any social or community activities without their parents or a staff member present. The other two participants came from large families and their siblings played a key role in keeping them safe in their local area.

Experiences of bullying or abuse occurred in a range of settings including school, college, housing estates and social groups. The level of abuse varied from verbal and physical bullying to sexual abuse. Laura talked about her school experiences of bullying:

There was one girl who used to bully me at school... and she got other girls to be nasty. She was like behind it all... I come home and just cried because I thought 'why is this happening to me?' I was petrified.

Similarly, Natalie explained how being verbally bullied impacted on her feelings about herself, especially when bullying occurred between friends:

Sometimes I get the feeling that I don't like myself... like whenever people call me names... One day I got called a freak... it makes me feel really angry and upset... Sometimes I feel sad if someone annoys me or says something like that to me that's not nice.

I: And what do you do when that happens?

Sometimes I feel I stand up for myself but most of the times I get really sad.

Ronan had been bullied as a child in the local housing estate, including an incident when he had been verbally abused and physically attacked. As Ronan grew up and began to stand up for himself, his mother was worried about his safety:

... in this park people would have been very cruel to him. When he would have been 8 or 9 he would have been coming in here and crying saying young people would have said different things to him and that he was different... they were very cruel... but they would say nothing to him now. As the years went on that all changed and he was fit to stand up for himself. I used to be afraid as the years went on because he would just have booted anyone if they had said anything to him.

Ronan also later experienced bullying at college and in the day centre he attended and explained how he now responds to those incidents:



**Just the odd time... but you just take it as people messing about and joking
Aye but not much. Just walk away. Just tell them to stop it that's all.**

I: And would they stop then?

Aye but then they might do it again. Just laugh at them and walk on or say something.

A worrying aspect of experiences of bullying is the lack of impact when some participants told another adult, as Callum explained:

I had a bully... He says something that annoys me and says silly things.

I: Right, and how did you sort that out?

By telling on him.

I: Yeah, so was it sorted out for you?

No because he is still doing it.

Likewise, Maurice felt unable to address bullying in his local college:

Actually they're always pushing me away in college – bad guys

I: Did you tell somebody about that?

Well I was going to stick up for myself. It didn't work... If I call the staff and tell they bully me for telling the teachers

I: So how did you sort it out?

Actually no idea

I: Does it still happen sometimes?

Probably a bit

Ronan was the only participant who experienced an effective response to a bullying situation when a staff member witnessed the situation:

It happened at the centre but the manager was there to tell them to stop it. They might get out and not get back for a while. They might have to say sorry or apologise. They might get suspended.

These findings indicate that young adults should be equipped with knowledge of their rights and a range of strategies to use to address disabling and abusive experiences. Open channels of communication about disabling bullying in educational and training facilities are crucial, and social work staff could also play a role in therapeutically supporting victims of abuse.

Professionals were aware of the vulnerability of young, disabled adults in the community and the impact negative experiences could have on future opportunities for social engagement:

Young people are either extremely sensitive and kind and helpful or can make life very difficult for a person with a learning disability, so if a person with a learning disability joins a group we need to make sure they are accepted, protected and cared for or they will be destroyed and carers obviously have a difficulty with that.

There is a need for awareness raising in local communities and continued efforts to address discrimination on the grounds of disability and to challenge mainstream providers to provide inclusive social opportunities for disabled young people.

Summary

Social exclusion is still a common experience for young disabled adults. Opportunities for developing and sustaining social relationships are restricted for a range of reasons including: limited access to inclusive and mainstream social activities; loss of social networks as service settings changed; and parental concerns about risk and vulnerability. There are also concerns about discrimination, bullying and abuse on the grounds of disability. Further efforts could be made to raise awareness of disability rights, assist disabled young people to develop effective strategies for keeping safe and increase the visibility of disabled young people in mainstream society. Further therapeutic support could be provided for disabled young people who have experienced disabling and abusive situations and a range of sectors need to work together to fulfil their responsibilities to address the social exclusion of disabled young people.

3.3.3 Balancing Adult Rights and Risks

Most young adults had the same aspirations as their non-disabled peers including, learning how to drive, developing personal relationships, getting married and having children. However, these expectations of adult life were rarely mirrored by their parents and professionals who had serious concerns about their son/daughter's vulnerability to risk and abuse. These contrasting perspectives raised dilemmas relating to balancing the rights of young disabled adults with consideration of risks.

Sexuality and Personal Relationships

One of the main areas of contention was the issue of sexuality and personal relationships. This was an issue that parents struggled with as they had serious fears about their son/daughter being manipulated, abused or experiencing an unplanned pregnancy.

I would have worries about her with men... if she finds someone who has an interest in her at all she latches onto them... she still doesn't understand it... she thinks that relationships are just talking or flirting. I know if anything ever happened to her she would be really scared.



A few parents expressed concerns that their son/daughter could appear to have more knowledge and understanding than they actually had which could lead other people to over-estimate their ability and increased their vulnerability:

It's really complex because she's very affable... but that really isn't what's underneath you know, because her understanding isn't as good as you think it is. People think 'Oh she's great, really capable' but she's not.

This was an issue for parents of sons and daughters. Ronan's mother expressed her worries about his relationship with his girlfriend:

She is quite advanced and very intelligent and funny... and then somebody said 'God forbid if she got pregnant or anything you would end up getting the blame'... I would always hope he would get somebody but... she's more advanced in years than him.

Yet, reflecting their life stage, most young adult participants talked about having a girlfriend or boyfriend:

I would like to officially meet and charm the girls... being in love is like somebody sitting on edge.

Others also expressed a desire to get married and have children:

I have a girlfriend... I'd love to get married because I would have... special in common

I: And would you like to have children?
I'd love to.

Callum kept a diary with a clear timeline for finding a girlfriend and having a sexual relationship in the future. He kept extending the timeline for achieving these aspirations, as his mother explained:

He always used to say that when he was 16 and then 18, he's going to get a girlfriend and then it was when I'm 20 and 21... because it doesn't happen.

Some parents had considered the rights of their son/daughter to engage in a personal relationship and others assumed that, due to the level of their impairment, they were not interested in personal relationships or did not have the maturity or competency required to understand or sustain a personal relationship. Others would like their son/daughter to experience being in a loving, personal relationship in the future but did not feel they were ready for that level of engagement or commitment at this early adult life stage:

She hasn't hit that age yet of interest in boyfriends. As a teenager there were boys that had an interest in her but no she had no interest in them... ten years down the line when she is maybe more mature I would like to see her having some sort of relationship with somebody who respected her..

Likewise, some young adults indicated that having a personal relationship was part of their future plan rather than a current goal as they did not feel ready yet:

I haven't had a really like proper boyfriend that can take me out... I would like to have one sometime but I don't know when. I don't think I'm ready. There's no rush.

Indeed, one participant indicated that she would prefer to be in control of decisions about forming a relationship in the future and did not wish to marry or become a parent:

I don't like boys chasing me. No. I chase them... I don't have a boyfriend.

I: And would you like to have a boyfriend?

Yes but in the future but not now. I am very busy

I: And would you like to get married?

No way. I won't get married no because I want to be a writer.

I: And would you like to have children?

No way. No no no. I couldn't cope.

Parents who felt it was possible for their son/daughter to engage in a personal relationship in the future emphasised that they would have to take steps to ensure they were adequately supported and safe:

He has talked about wanting to have a girlfriend... if it ever got to that stage they would have to do it under our roof or somebody else's roof because there is still that element of care you have to put there. The idea of him living in a flat somewhere with somebody on their own, no, I just can't see it...

They also wanted to ensure that they did not undermine the wishes and feelings of their son/daughter or make them feel unequal to non-disabled siblings or peers:

I heard her saying to her sister that she wanted to get married first and then have a baby. Yet in a flash she can come back to reality and say 'I'll never get married' or 'I would never have children how would I look after a baby?' She sort of goes into two wee different worlds... I go along with it and if she is on a day that she realised that it might never happen, I say 'Look at that lady that had no arms and no legs and she had a baby and she managed all right you will always get help in'.

In three cases, young adults had established a personal relationship and others were making efforts to do so. However, they were unsure about the next steps and how a relationship could further develop in the future.

I think I've actually got a boyfriend...I don't know how to ask him 'is this something else more than friendship?' because I don't want to scare him off...



There were also some cases where young adults were attracted to someone but did not know how to progress the relationship:

Well actually at college... I see this girl and she's interesting to me... I am sad about relationships with my girlfriend because it makes me embarrassed to ask a girl...

Similarly, some young adults had been approached by peers who were attracted to them and they were unsure how to respond.

Interestingly, several young adults (both male and female) emphasised that they would prefer a non-disabled partner:

I would like a girlfriend if she's fit and hot.

I: Would it be okay if she had a disability?

No... I don't want her to behave like a moron... I don't really like any of the special needs kind of girls.

Young adults were trying to make sense of their feelings and desires in a range of contexts but often under the supervision of adults who were concerned about risk and protection. Some parents ignored the subject and had not talked to their son/daughter about issues relating to sexuality or personal intimate relationships. This was the case for Robbie's mother, even though he had a girlfriend:

We had a wee party here at the house... they sat with their arms around each other and looking into each other's eyes and I couldn't cope... and he keeps saying that she is his girlfriend...

I: Have you talked to him about sex and relationships?

No we haven't, I would say it comes up at school.

I: And has he asked you about it?

No and I think I would die if he did... although he is 20, I can never see him in a relationship... I find that hard with all the children though.

In other cases, parents had broached the subject with their son/daughter and emphasised the importance of a loving relationship rather than sexual activity. It is also notable that most young adults had progressed through puberty and adolescence with a general uninformed assumption from parents and community based professionals that schools were addressing personal and sexual education.

Two young adults had accessed personal development programmes addressing some of these issues. However, in both cases, parents had ended their son/daughter's participation in the programme due to concerns that they were misinterpreting information or being taught about rights without consideration of their understanding of risks or consequences.

Several parents felt that early adult life was a difficult stage for their son/daughter when previously acceptable expressions of affection and physical touch were now viewed

as inappropriate behaviour in young adult life. Professionals also commented on how expectations of behaviour changed as disabled young people moved into adult life. Indeed, several parents and professionals shared examples of instances when innocent behaviour was labelled as sexually deviant. One mother felt that her son was labelled inappropriately following a minor incident and was concerned that different standards of acceptable behaviour were applied to disabled and non-disabled young people:

I think one of the lowest points was when he thought it would be a good idea to moon on a school outing. That became a huge issue... he was put on a sexual register for the school... and none of the children were allowed to go near him and I thought this is just ridiculous... they told me in the school, if this was a normal school this wouldn't even have been an issue... So in a school with mental handicap it is! They were very judgemental and just pigeon holed him as a deviant...

Professionals also recounted cases where sexually inappropriate behaviour caused difficulties for young adults:

With learning disability, what is regarded as appropriate touch is acceptable up until a certain age, all of a sudden you become a young adult and you are a deviant and that can be problematic for young men when they hit that 15, 16 age group... the frustration they feel at being misunderstood or not being taken seriously in terms of the strength of their feelings and even just how they are regarded and how people respond to them.

Although the majority of young adults had developed or expressed an interest in personal relationships, very little work was being undertaken with young adult participants in relation to their sexuality or potentially developing personal relationships. Some practitioners were involved in assisting with arrangements for contraception and addressing issues relating to inappropriate sexual behaviours at an individual or groupwork level. However, staff were often unsure how to balance rights and risks in relation to personal development and sexuality and were reluctant to challenge overly protective parents:

Parents of people with a learning disability do have greater control.... .. if there is any hint of personal relationships, parents can sometimes put a handbrake on them, they don't want to accept that they have feelings and emotions and there is nothing there to help us balance that... we still have no policy on it, but staff do their best to try and educate and advise.... it continues to be a minefield.

In cases where parents and professionals were concerned about the wellbeing and safety of a young adult, they relied on vulnerable adult policies and procedures to guide practice:

You have to take them down the vulnerable adult route... we have had to tell one girl that she couldn't marry this particular guy... we had to say the psychiatrist doesn't feel that your daughter has the ability to understand



fully what it would mean to be married, to have children... it was probably one of the hardest things that I've been involved in.

Professionals Balancing Rights and Risks

In addition to issues relating to personal relationships, professionals found they were often balancing rights and risks in other decisions affecting post-school options for young disabled people. Linked to this was the complexity of negotiating with protective parents. Interestingly, some professionals noted how much services and practice had developed over the years with new generations of young adults and parents challenging service providers to be more inclusive and risk taking. However, professionals were most challenged when they were aware that a young adult wished to have more opportunities in their life but were restricted by their parents. For this reason, professionals emphasised that it was crucial to work alongside parents:

It's trying to get a balance really... you have to take risks for people to achieve... and the carer can't make a decision for another adult... parental rights are actually diminishing rights and a lot of parents do not accept that, there is an enabling that needs to happen... often parents become a bit over protective because of the experiences they've had so we try and bring the parent along...

There is a danger of ignoring the voice of the young adult in these situations as parents have much control over their lives. Whilst, professionals were aware of the human rights of young disabled adults, they were also acutely aware of the amount of control parents exert over life choices:

A person with a learning disability has the right to determine how to live their life, have relationships with whoever they choose and that is enshrined in law. That is all well and good but they live with Mummy and Daddy and they don't allow it. Whose agenda gets followed? You can understand the parents' fears... parents have taken decisions all their life... it's an enormously difficult area and no matter what you put in place to ensure that it is the person's own views that are being heard... you are very largely dependent on parents.

There was an unclear balancing act for professionals as they knew that parents needed to be encouraged to allow their son/daughter to take measured risks but were also dependent on sustaining a good working relationship with parents who had the power to hinder or facilitate access to support services. Working at the pace of parents seemed to be a common approach to ensure they stay involved and feel that small changes are incrementally introduced to reassure them that their son/daughter will not be at risk of harm. In some cases, social workers also worked with young adults and parents to develop their insight into risks and how to stay safe:

We had an individual who is now an adult and their parents are not happy with them doing certain things and still see them as a child. The key worker is getting them to understand the risks and indicate that they can manage that risk saying to the parents he is a young adult and it is within his rights to want to do that... It is a different shift for parents and there is a role of letting go...

Professionals were also beginning to refer young adults to psychology for capacity assessments to determine a young adult's capacity to make decisions which could support their efforts to encourage parents to allow their son/daughter to make self-determined life choices.

Access to Advocacy

Given the complex ethical dilemmas facing professionals in relation to upholding the rights of young adults and ensuring their wishes are respected, advocacy was an important aspect of practice. There was a general consensus that there is a growing focus on inclusion, rights and choice. Indeed in some Trust areas, service user groups had been established to raise awareness of and champion their rights and were also helping to advise young adults, parents, schools and other professionals. However, at an individual level many of the cases professionals described highlighted situations where the views of young adults were not heard or responded to. In such cases, greater access to advocacy services may help to ensure independent support and representation of the priorities for young adults. Such advocacy should be grounded in a rights-based, capacity building perspective but must also take into account the complex context of the lives of young, learning disabled adults and the concerns of parents and professionals.

Some social workers emphasised that a key aspect of their role as a key worker is to advocate on behalf of the young adult at various levels. A few social workers took this role very seriously and, in the context of budgetary constraints and tighter eligibility criteria for access to services, they felt that their advocacy role was crucial:

That is one of the first things that the job is about.... not only advocating to their own parents but to our own Trust services or in meetings... you are very clearly advocating for their voice to be heard.

One of the ways that social workers advocated for service users was through their assessments of need and reports submitted to resource panels who made decisions about access to services. Social workers were not present at such meetings but they tried their best to present a comprehensive case for the families they worked with. This often meant that social workers were disappointed when decisions reached were not compatible with their recommendations or did not seem to be adequate to meet the assessed needs of the service user. It also involved spending more time completing administrative forms and reports:

It is my job is to assess need and if it's there I will say that's what is needed... I spent 5 solid days filling out a UNOCINI for a family that needed a big package of care and I got every penny... It was a good outcome and helped that family... but, in this day and age, is that what you have to do? The amount of time I sat at my desk in order to get that outcome is sickening.

Senior managers recognised the role of key workers in advocating for service users but emphasised that there is no statutory duty to advocate and difficult decisions about access to services must be made on a wider basis and in the context of resource constraints:



We don't have a statutory to advocate... I think social workers misplace the role of advocate and rely too heavily on it... We have a helicopter view of the entire service... and to a large extent we can't deliver because we have no money.

Indeed, some senior managers made efforts to share information about the availability of resources and spending priorities with key workers so they were informed about the reasons for limited access to services.

Some social workers indicated that they would prefer to bring in an independent advocate and others felt it was important to offer a choice as some young adults would not wish to involve another new person in their life. One respondent also suggested that independent advocacy is important to avoid key worker bias due to knowledge of limited available resources:

The social worker going into the house has so many pressures on them. They know that there is no money for this person so they go in trying to do a person centred assessment looking at what the outcomes are but there is no way of getting there, so those are constant challenges for the social worker on the ground. But bringing advocates on board will open more avenues.

However, the availability and appropriateness of independent advocacy services across Northern Ireland was limited. There was also concern that existing advocacy services were not tailored to the particular needs of young, learning disabled adults.

Summary

Most young adults had aspirations to engage in personal relationships however, parents and professionals were concerned about their vulnerability to abuse or exploitation. Interestingly, reflecting their capacity to judge their own level of understanding, some young adults felt they needed more time to mature or engage in other interests before they formed personal relationships. Both parents and professionals found it challenging to address issues of sexuality and personal relationships and were torn between balancing the rights of young adults with their duty to protect. Some professionals were clearly focused on prioritising the views and wishes of young disabled adults but were also managing complex working relationships with parents in the context of scarce resources. The development of more independent advocacy services tailored to the needs of learning disabled adults would help to ensure their rights are upheld and they are supported to express their views and influence decisions affecting their lives.

3.4 Adult Services

For most young learning disabled people the transition to adult involves engagement with adult learning disability services. All, except one, study participant had transferred to adult services. This section reports on their access to adult services, including short breaks, direct payments and continued social work support.

3.4.1 Short Breaks

The provision of adult short breaks varied across Trust areas. For example, in one Trust the main short break type was family-based shared care, adult foster placements or domiciliary support in the family home. In contrast, in another Trust area, the main provision was residential with very few opportunities for family based short breaks unless they were continued from children's services using direct payments. In a third Trust, in some areas there was a heavy reliance on residential short breaks and in others there was more flexible domiciliary and host family provision. In the fourth Trust area, variation across regions was also noted with great demand for one residential unit.

In areas that depended on general residential services for adults of any age, there was a reluctance to avail of residential short breaks and the availability of accessible residential short break services was very limited for young physically disabled adults. Senior managers and commissioners indicated that there is a shift towards developing community based options that would promote social inclusion rather than a continued reliance on the limited availability of residential short breaks. However, there was limited evidence of such approaches for the participants in this study and key workers did not indicate that developing community inclusion initiatives was a current aspect of short break support.

Most study participants experienced consistent short break provision as they moved into young adult life. Only two young people had experienced a delay in short break provision in the transition to adult life because local or inaccessible services were not available. However, after a short period these participants regained access to new short break opportunities. Although this consistency in short break provision was a positive finding, it was noted that fewer and more expensive short break services were available in the adult programme of care. In addition, most young people moved from familiar children's short breaks to adult facilities with a mix of ages and abilities and a different culture of care. Many young adults found it difficult to end children's short break services:

I got too old and the Trust won't keep me going there... I hated stopping. I actually cried...

Many parents reflected on very positively on children's short break services and the legacy their input had on their son/daughter's adult life:

They were absolutely brilliant... they did everything possibly to accommodate him and to get his social mix right and it paid off. I was very sad to see that tying up... I don't know if the carers were aware of the great affect they had on him but certainly he learnt a lot from them taking him out... how to interact socially with people... I do value all the hard work that went in all those years.



Parents of young people who continued to avail of the same short break carers in adult life were particularly pleased to with the consistency of service provision:

We have been so lucky and she does give it her all... when we collect him the TV is always off and they are both sitting chatting about just everything... any problems that happens in school and college and he would tell her... and she can say to us which is great for us.

Young adults who continued to use family-based short break services were very happy with this service as it provided consistency at a time when most other aspects of life were changing. For example, Robbie was very close to his short break carer:

I feel happy. I like it so much. I love her because she's part of my family.

The continuation of shared care arrangements in some Trusts was also noted by professionals. However, such consistency was not replicated for those using residential short breaks and future funding for continued shared care services was questioned in the current climate of budgetary cutbacks.

Young adults who moved to adult residential short break services found it more difficult to settle in:

It's ok. It's not as nice as X [child short break facility]... I still don't like it. It's boring.

Ronan explained why he felt sad when he went to stay in a residential short break facility:

You miss people... and then you get on with it... but if you're away too long you miss what's going on.

In children's services, young people often met familiar peers at short break facilities however in adult services they did not know other people and did not find it easy to develop friendships as they had less frequent (but longer) stays and were mixing with different people each time. As a result, accessing short breaks in adult life for block periods was difficult for both young adults and their parents. However, young adults were reluctant to complain about these services because they knew their parents needed a break from caring roles. For example, Edel had a negative experience of a sitting service but was willing to try it again because she would like her parents to have a more active social life. Likewise, several parents acknowledged their son/daughter only continued to use short breaks to give them respite:

She likes it okay... She knows it gives me a rest but I know she would rather be at home.

Some young adults accessed domiciliary support services involving home visits from a carer or social outings in the evenings or weekends. Most young adults enjoyed these opportunities, particularly when it involved going out or engaging in social activities. Some young adults had developed close relationships with these carers, as Maurice explained:

My best man. He is brilliant as a friend. We have a few plans... shopping, cinema, bowling, archery... It's like amazing.

Maurice really enjoyed this short break provision however he also stayed at a residential short break facility occasionally and described not being happy there:

It's stupid... A total disaster... actually bored and sad... like left me alone... and angry... the other girls there are not the boss of me. I am the boss of them.

Young adults who accessed new adult services, particularly personal care support, initially found it difficult to adapt to new service providers as Laura explained:

It was a bit hard when they started doing personal care calls... You're always clock watching to know how much time you have left until they come. The people are all different... At the start it was really hard... now it's not as bad.

In the previous study some parents struggled with the decision to send their child to stay at short break facilities and, interestingly, this was still the case in adult life due to a strong bond between parents and their disabled son/daughter, as Ronan's mother explained:

It gave me a wee bit of a break... but I would be sitting out in the kitchen chatting to myself... I kept thinking if he was here he would be blathering away. I did miss him now and I would be talking about him and I did miss his company.

Summary

There was variability in type of short break provision within and across Trust areas. All participants in this study who used short breaks as children were able to access short break services as young adults. However, some experienced delays in access to these services and others noted that short break adult services were for shorter periods and not tailored to the needs and interests of young adults. Further attention could be paid to the provision of age appropriate short breaks for young disabled adults which may involve a shift towards more community-based provision rather than residential services for adults with a broad range of ages and needs.

3.4.2 Supported Living

None of the participants had experience of supported living arrangements as they were all still living at home with their parents and most participants expected to continue living with their parents for the foreseeable future. Parents also usually assumed that their son/daughter would remain living with them until they were unable to care for them:



There was a stage in my life where I thought I would like him to have semi-independent living. I'm not so certain I would want that now and I don't think he would want it... he actually loves being home with us... he is very verbal about the fact that he really doesn't want to go away from his home...

Other parents were worried about upsetting an existing routine that worked well for their family.

Interestingly, when this subject was raised, some young adults seemed to be considering it for the first time. Ronan initially stated he would not be able to live on his own but then began to question this assumption:

I couldn't live on my own... well I don't know... I could make tea but I couldn't make my dinner. I would need somebody to take me up sometimes. I could live on my own, aye.

Some respondents expressed a desire to live independently but still remain in close proximity to their parents:

I would like to find a place of my own but not far from Mum because I don't really like moving away from Mum... My Mum and family would help.

As Natalie indicated, young adults who did not have access to information about supported living options assumed their immediate family would still need to provide care and support. Those who had experience of receiving carer support were more aware of alternative sources of support outside their family circle that could facilitate a move to more independent living arrangements. For example, Laura wanted to have her own house in the future and indicated that carers could come into the home to help with her personal care needs instead of her mother.

Parents were concerned about the vulnerability of their son/daughter and potential risks associated with living in a supported or independent living arrangement. Some parents also reflected on how difficult it is for them to 'let go'. For example, Callum wanted to live on his own in the future but his parents had mixed feelings about this move, with his main carer being most worried more about the potential risks.

I would like to see him when he's 30 living in some kind of sheltered place but his dad wouldn't have it... it's harder for him to let go... because he presents so articulate you can over estimate his ability and he wouldn't be able to plan out his money or get a bus by himself and so they have to be careful about risks as well.

Two parents also raised an important point about expectations that learning disabled young adults would be happy to live in communal housing arrangements when non-disabled young adults are expected to move into their own homes:

I would want her in a sort of small group situation... but one of the biggest problems is getting people who are compatible to live together... You get to the stage you just don't want to share houses with other people anymore.

You just get fed up having to adjust and adapt, and to think that somehow people with learning disability should be able to do it I think is very unfair. We expect an awful lot more from people with disabilities than we do of normal people.

Most parents suggested that a move into supported living was something they had expected for their son/daughter at their current stage of life but this aspiration was not realised due to the lack of available supported living options. Parents had very little information about supported living opportunities and indicated that few were available:

There is supported living for a small number of people, it's a drop in the ocean, and you are basically told that until somebody dies there isn't a place....

Key workers and team leaders also indicated that there was a shortage of funding and availability of supported living options. Some Trust managers suggested cross-sectoral supported living schemes in their area were successful but too expensive to roll out for the full population who could avail of such services. There was a general concern that resources in this area were targeted at the re-settlement of people from hospitals rather than meeting the needs of young people planning to move out of their family home.

If they gave us extra resources we could have more young people in assisted living because we have all the providers set up but we don't have the money to do that, the only money we are getting is the resettlement money.

However, other managers indicated that service developments focused on meeting the needs of those resettling from hospital care into the community may create opportunities to enhance provision for a wider range of disabled people:

The human rights of people being resettled from hospital shouldn't overcome the rights of other people to live a life in the community. With the money for re-settlement we have tried to argue that, as long as we can meet the target for people coming out, a portion of that money should go to community services, like day opportunities, short breaks, and specialist support. Those strands of community infrastructure that support people in the community...

Meeting the needs of young adults who are not able to live in private rented accommodation with support is a key challenge as supported or residential accommodation is limited. In addition, young adults who present with additional needs requiring specialist or adapted accommodation are even less likely to access supported living provision:

Prioritisation for supported living or residential accommodation is going to those in the greatest need... and if they have physical needs and need a lot of support, it would need to be specialised accommodation... and purpose built facilities... but there just isn't the facility for them to move to.



Summary

Young adults and parents have very limited knowledge of supported living options and there is a lack of support living opportunities for young learning disabled adults due to limited provision and the prioritisation of other groups. Further development of supported living programmes is required to enable young learning disabled adults to fulfil aspirations to live independently or with support in the community. This is an essential part of building the capacity of young learning disabled people to develop independent living skills and planning for further transitions in adult life when parents are no longer able to continue with caring roles.

3.4.3 Direct Payments

Direct payments were a new approach to service provision that had been introduced since the previous study. Three parents had no knowledge of direct payments and five parents were aware of direct payments but did not have accurate information about the process of using them. Some parents were concerned that they would not be able to identify someone who could provide support funded by direct payments (a particular issue in rural areas) and others were unaware of the available support to help them arrange and maintain direct payments. The remaining parents had considered direct payments and decided not to use them usually due to a reluctance to become an employer and concern about the extra pressure of fulfilling the legal and administrative processes linked to that role. The other reason for not pursuing use of direct payments was concern about re-assessment and losing current services.

Only two parents in the study used direct payments. One parent used them very flexibly to recruit carers who could facilitate a range of social opportunities and support for her daughter, although she acknowledged that it was time consuming and required a range of organisational and administrative skills. This parent had identified carers through word of mouth recommendations followed up with meetings to check their suitability. The other parent who used direct payments paid a family member to provide short break support. She was initially concerned about how she would manage financial matters but had been well supported by the Centre for Independent Living.

Most professionals perceived direct payments as a positive and creative approach to service delivery but recognised that some families simply did not have the contacts, time or capacity to manage direct payments:

Some families just don't want the hassle of trying to sort out direct payments... because there is an awful lot of work in it... it is a job in itself and if you are managing a person with a challenging behaviour you already have a lot of pressures....

However, with the shift from traditional day care to day opportunities, a higher number of younger parents and carers were willing to consider direct payments as a pathway to more creative community-based day activities.

Some practitioners suggested that families may be receiving inaccurate information about entitlements to direct payments and emphasised that, although there is increased choice and control, the budgetary implications still need to be considered by the Trust in advance. Many Trusts were using carer assessments as a way to access to direct payments however, this link was sometimes unclear:

You have to have an assessment to get a direct payment so a number of our carer assessments have led to direct payments to help the carer out... but there is confusion about that... direct payments are about providing funding to a person with a disability or their carer so the key worker will undertake a comprehensive assessment of the needs of the individual or a carer assessment... and the two can be separated.

Indeed, some professionals were concerned about this shift back to meeting the needs of carers rather than assessing the needs of young disabled adults:

The other avenue... is to target the direct payment at the carer in based on a carer's assessment but that is at odds with the notion of enabling people with a learning disability. That's an unresolved issue.

Most Trusts suggested that the uptake of direct payments was not as high as they expected. The reasons for the slow uptake of direct payments were multiple. Some key workers were reluctant to encourage carers to proceed with direct payments when the resources required were not available:

Staff are quite reluctant to go and offer something to someone that they know they can't fulfil... the problem is that the Trust is trying to take direct payments out of existing budgets... there's no resource there

A judicial review decision regarding capacity and use of direct payments was also cited by most managers and practitioners as having a major impact on the extent to which direct payments were offered:

The judge made a determination that the person a direct payment was made to didn't have the capacity to manage the direct payment... of those who had direct payments in the last year in our Trust only 4 had capacity, so now we won't be giving a direct payment to somebody without capacity... the direct payment policy and funding implications were not well thought out.

As a result of this judicial decision some practitioners were confused about the process of direct payments:

It would be very hard to get direct payments through now because of all the capacity assessments... We haven't been able to pass any new ones in the last 2 to 3 months... I'm not 100% clear about this issue so I think there needs to be a bit more clarity...



Interim guidance was provided for Trusts on how to deal with applications for direct payments pending a change in legislation linked to capacity, including appointment of a controller or power of attorney through the Office of Care and Protection. However, there still seemed to be a reduction of direct payment applications and unresolved concerns about capacity issues:

I fully understand the official judgement... but referring to the Office of Care and Protection could be seen to mitigate against what we are trying to do in the first place which is to ensure that families have got care and control... and we are moving very quickly to an expansion of individual budgets and self-direction...

Senior managers were hopeful that the introduction of new mental health and capacity legislation would provide legal direction on capacity. However, several managers queried the emphasis on measuring capacity:

We had got to a stage where we were encouraging people to presume capacity... that is still the right approach... How much capacity do you need to be able to choose between a service that is person centred or not? And managing the money is so tight anyway as your bank account is monitored and you can trace it all the way.

Likewise, a social worker highlighted issues of inequality in access to services when capacity was the deciding factor:

We have been told that if there is a question about capacity then we shouldn't be accessing direct payments for them... it is so discriminatory... just because someone else is making your decisions you can't access a service. How unfair is that? Somebody who can't make a decision can't have that service. We need to ask if that person can't make a decision, how do we make a decision that is in their best interests, how do we give them a voice?

A major factor impacting on access to services and activities was transport. There was little support for use of direct payments to fund transport and assessments did not consider transport needs. However, some professionals suggested that, flexible use of direct payments and self-directed support could possibly fund transport to a day opportunity:

We wouldn't assess someone needing a direct payment for transport. We would be talking about the care and support aspect, not the transport aspect but it is how they use it, they might put some money to that... it is up to them to save up and do that... to decide what they need.

Some professionals reflected on how the move towards personalisation in Northern Ireland may provide more creative ways to access support for transport. Projects were in place in some Trust areas to pilot self-directed care approaches and personalisation however, these were constrained by the absence of policy, a narrow focus on improving direct payment targets and a reluctance from some service providers to risk trying new ways to fund services. There was also some uncertainty about how prepared the various sectors in Northern Ireland were to develop sustainable and creative services to support the implementation of personalisation:

The personalisation agenda still has a long way to travel... I'm not sure if the services in Northern Ireland are already there to support people to be creative... it is about finding the money... and it is back to this whole health and safety issue.... the changes in social security and benefits will also impact on personalisation in a detrimental way.

Some respondents also indicated that personalisation may be difficult to implement because of a culture of dependency on health and social care services:

We have a different, dependent culture... social security and social services are a safety net... if I need help then I go to social services... we move into people's lives and remove all the risk... so it will be a huge challenge...

In addition, managers emphasised that resources in Northern Ireland were invested in buildings rather than community-based support which was very difficult to rebalance.

Summary

Whilst some parents and professionals were positive about the introduction of direct payments in Northern Ireland, there has been a slow uptake and a sharp decline in use of direct payments following a judicial review decision. Practitioners were still unclear about the policy guidance on use of direct payments and further guidance is needed on capacity issues in the context of learning disability services. There is a commitment from managers to develop the personalisation agenda in Northern Ireland. However, there are ongoing concerns about capacity assessment, freeing up resources and addressing cultures of dependency.

3.4.4 Social Work Support

As the first study explored social work support for learning disabled children and young people, it was important to re-examine the level of social work support available for the participants following transition to adult life. All participants, except one, had a named social worker in adult services. Lorraine and her family had agreed to end contact with social work services when she turned 18 years as they felt she did not have any needs requiring social work support. Whilst a few young adults had a good working relationship with their current social worker, most of the nine participants who had a social worker had limited current contact with them or knowledge of their role:

I don't know about the social worker. I don't know anything about that

However, young adults could recall a range of social workers over the years and highlighted those who made efforts to get to know them and develop a relationship with them. For example, Ronan had five social workers over the years. He could not recall the two most recently allocated, however, he fondly remembered two previous social



workers. He had very little to say about his current social worker and only saw her when she attended reviews at the day centre:

She comes down to the centre an odd time

I: Does she talk to you down there?

No not much. She talks to staff mostly.

Likewise, his mother had very limited contact with a social worker now but recalled a strong working relationship with their previous social worker who had regular contact with the family and responded quickly and effectively when issues arose:

He was very good because we would have quite different problems here and he would have come out... and get it sorted out and phoned me back... no problem. But I would never see the current social worker from one end of the year to the other... if I needed anything I would just have to ring them... but it's only me asking... I would just like for them to come out once or twice a year just so they know what's going on and to see does he need anything.

Parents and young adults clearly identified the social workers who had made efforts to listen to them and advocate on their behalf to access services. Young adults had very positive comments about these individual social workers:

He's cool... He found me a job... Oh and he found me a school

She's like a friend... She just talks about my exams. She always talks to me about the things I did.

She was very nice... she helped me with different things or if I need anybody to talk to... she arranges things for me.

She's amazing. I don't like her. I love her... she's got my life and she's working for me and looking for jobs... She's a bit stubborn about 'grow up!'

He's really nice. He's trying to build up my confidence. It's working... I would be straight forward with him like how I feel like.

Laura described having both positive and negative experiences of social workers over the years:

The last one was useless. The one before that was just as bad. Then I had X. She was nice. She got me into tech and the centre.

Similarly, parents reported mixed experiences of social work support. Most families had been allocated to different social workers over the years and were able to reflect on their different approaches. Those who were positive about social work support had regular and proactive contact with their social worker and could specify situations when their social worker had provided valuable support and advice. Reflecting the views of young

adults, parents also valued social workers who invested in relationships with their son/daughter and their family.

Laura had many different social workers and experienced gaps in provision when she had no key worker due to staff changes. Her mother emphasised the importance of social workers having a caring, advocacy approach to working with disabled young people and their families and promptly following up on agreed actions:

Some social workers weren't as good or they would promise you things and you have to keep ringing to see what was happening... The one we have now has been brilliant... she seems to understand your needs. You know loads of people can listen to you and walk out the door and forget about what's going on in your house but she doesn't and you know she sees what's going on and she cares about what's happening in the family... she really fought hard to get the extra support we needed.

For parents, variation in social work staff was not problematic as long as each social worker showed an interest in supporting their family and advocating on their behalf:

Everybody has a different style of social work, of relating to the family... but I felt they were very much on our side... and whenever we were in difficulties the social worker was very supportive and very good.

Parents were particularly satisfied with social workers who had knowledge of service options and systems, provided advice and signposted them to other appropriate supports:

There is no doubt having the expertise of someone in the system to highlight things for you is invaluable... it could be a lifeline... you are dealt a card having a disabled son and it's like nothing else around you, you haven't a clue, you don't know who to see, you don't know how you are going to survive... To have a social worker there that will pitch it for you, saying this is what you do, this is the form you fill in. Honestly it's like a path through a jungle, it's brilliant. And we have been very lucky and got really good people... Our current social worker is great, she has all these ideas and she told us about things we wouldn't have known about so that was very good.

Similarly, two families who had been able to keep the same social worker from child to adult services were pleased with this consistent service:

He was able to keep on us on his books... you know that you can call up and they know what you have gone through rather than having to sit and explain everything over... He has been very good.

However, other parents who had limited contact with their social worker were much less satisfied:

I just feel that unless you keep ringing they forget about you... you have to hound them and you don't get the answers. When I phoned to get advice



they couldn't help... you sort of get despondent and think, what are you there for? You are completely on your own.

Parents who had one-off contacts with social workers following a crisis and did not have any follow-up support felt particularly disappointed and expected social workers to be more proactively involved with their family:

I have only had social work contact in emergencies whenever I begged for it and they never followed it up... they haven't been supportive at all. I had to push and push and push and there has been no come back to see how it worked out... not a thing. I am very disappointed because... she was going through a rough time... and there was no involvement all...

Some parents felt they had been abandoned by social services when staff changes occurred and they were not allocated to new key workers at key transitional points:

We lost our key worker years ago because the social worker was off on the sick... then the next one was promoted... so we just battered on ourselves... there was for a period of time from secondary school to college when we wouldn't have had anybody. Then when I rang up and I was told I wasn't allocated to a new key worker... and it took ages for it to be done.

Staff interviews highlighted the impact of increased administrative requirements and changing systems of record keeping on the time social workers had available to spend with families:

There is a huge amount of documentation to be completed. There is an assessment, a carer's assessment, a risk assessment... it may lead to a comprehensive assessment, you need to fill in a form for a domiciliary payment, a direct payment, there are reports to be done left, right and centre and referral forms... You would like to be able to spend more time with families but because of so much bureaucracy you can't, the volume of paperwork and the red tape can take over...

Staff also felt under pressure in the context of continual re-organisation and change of policies, procedures, staff and targets:

There has been the reorganisation of the Trusts, introduction of new policies and procedures, new targets and performance management priorities, new assessments and a lot of change in personnel... and it can carve away at the traditional role that the social worker had... staff are being pushed to meet targets and that's a difficulty because as a profession social work wasn't designed to work at that level... social work has a much wider remit...

This changing role of social work was also in the context of limited staffing resources and reduced Trust spending:

The statutory social work role has changed... how person centred can you be with the pressures of knowing what the budget is? As the resource of

social work gets spread thinner there is a change in the roles and functions that an individual social worker can perform...

There was also concern about caseload management and prioritising allocation to a key worker as referrals were constantly coming in and cases were not closing. Staff were also expected to take on additional caseloads when colleagues were on leave or seconded. In addition, individual social workers had developed specialist expertise in a particular area, such as safeguarding vulnerable adults, and were expected to undertake additional casework in that area on top of their existing caseloads.

As a result of these changing contexts and pressures, social work was perceived to mainly involve the co-ordination of assessment, referral to other services and resource management, rather than a direct service to young adults and their families:

In my view there has been a significant erosion of the social worker role. We have become assessment co-ordinators... the 'rationer' of scarce resources. There was always an element of that in social work but is a much bigger element now... in truth we have turned several of our disciplines into resource managers, resource rationers.

There was a general view that the therapeutic role of social work had been eroded as they now made referrals to other professionals rather than undertaking direct work with young adults themselves:

You don't get the opportunity for therapeutic work because of the paperwork, if there was any specific need it would have referral to psychology or other organisations or teams for specific work with that young person.... we need to release professional time to do professional work.

Indeed, a voluntary sector manager indicated that social workers generally had less frequent contact with young adults:

We would have quarterly reviews and quite often you are finding that the last time the family had seen the social worker was at the last review. And nowadays social workers are not even available to attend...

Social workers also raised concerns about recognition of the unique role of social work in the context of multi-disciplinary, integrated team approaches. The multi-disciplinary approach to key working blurred professional roles. For example, in most Trusts nurses or social workers could be named key workers. Although the aim was to allocate nurses to cases with clinical or health care needs and social workers to those with social care needs, in reality, due to high caseloads this was not always the case. Indeed, in one Trust, cases which were not complex were managed by a day opportunities co-ordinator instead of an allocated key worker. In another Trust, social work assistants rather than qualified social workers were fulfilling the role of key worker. Such systems meant that qualified social workers only became involved when needs were challenging and requiring more intensive support or when crisis situations arose:



It can be a very reactive service when a parent picks up the phone and says we are in a crisis then there is a response rather than traditional proactive relationship-based social work which was trying to avoid that.

However, most social workers would like to see a shift back to a model of social work practice that prioritised direct and therapeutic work with families:

Social work needs to re-focus on the therapeutic and the independent piece, building sustainability and resilience in families...

Summary

Young adults and their families reported mixed experiences of social work support over their transitional years. Social workers who had made a difference in their lives had: maintained prompt and regular contact; taken time to develop relationships with them; prioritised the views young adult; signposted them to other sources of support; and advocated on their behalf. Some families were not satisfied with the level of social work support they received due to inconsistent contact; lack of follow up following a crisis in the family; and breaks in access to a social worker at key transitional times. Social workers expressed frustration about the demands of bureaucratic tasks, increasing caseloads and their changing professional role. Most social workers would like to have more time to spend with families and opportunities to undertake direct, therapeutic and preventive work.

3.4.5 Assessments, Planning and Reviews

Young adults and parents did not have detailed knowledge about assessment, planning or review processes and, in many cases, they were unsure if they had been undertaken. Indeed, a couple of parents did not know there would be a case file for their son/daughter until they were asked to participate in this research. Parents led very busy lives and often had multiple or intermittent contact with professionals so it is not surprising they were unsure about formal processes. However, information about assessment, care planning and reviews could be shared more openly with families. Indeed, one would expect young adults who have participated in person centred assessments, planning or reviews to have copies of such documents since they are supposed to be service user led.

Assessment

Assessment was a core aspect of social work practice in terms of collating information about need or risk and drawing links to appropriate services. Most Trusts maintained a traditional care management approach to assessment which usually involved comprehensive assessments for complex cases and shorter assessments for other cases. The complexity of need and likely impact on resources was the main driver for a more comprehensive or multi-disciplinary assessment. When there was any doubt about a young person's eligibility for access to adult disability services, a re-assessment could

be requested. The eligibility criteria for access to adult services were tighter than those for children's services so this process could result in a decision that the young person would not gain access adult learning disability services. However, in this study, only one young adult did not access adult services and this decision was reached jointly with the parent and adult services team.

Most senior managers recognised that there was variation in assessment approach within and across Trust areas. Efforts had been made to harmonise approaches but this was still work in progress in some areas. Given the complexities of balancing rights and risks (outlined in previous sections of this report), clear and comprehensive risk assessments were very important. Some adult learning disability teams had developed their own approach to risk assessment rather than using a standard regional model. There was some concern that standard risk assessment formats in both child and adult services were very lengthy which only suited complex cases requiring a comprehensive risk assessment. Other professionals also played a key role in risk assessments impacting on the lives of young adults in transition. For example, occupational therapists undertook risk assessments relating to independent travel which guided decisions on whether or not a young adult could access day opportunities requiring use of public transport. Cases were also referred to clinical psychology for risk assessment relating to behavioural or self-harm issues.

Carer Assessments

Despite continued caring roles, only one parent in the study had a carer assessment and could not recall the process or outcome of this assessment. Another parent was not sure if she had accessed a carer assessment but there was one held in the case file. Staff were encouraged to offer carer assessments but, in most areas, there was a slow uptake. There was a general view that carer assessments were more useful for new referrals as existing carers may not see the relevance or benefit of another assessment process. In particular, parents and professionals indicated that, due to resource constraints, there were often limited outcomes from a carer assessment in terms of delivery of services to met identified needs:

We do them more routinely now with new cases... people tend not to fill them out because there is a view that are no resources... people think why would I bother filling out that form if it is not going to make any difference.. what is the point when the resources are continually being cut?

However, a few professionals noted the value of 'building evidence' on the needs of carers to support requests for care packages. It was also suggested that plans to draw stronger linkages between short break provision and carer assessments may improve uptake of carer assessment and outcomes for the carer.

Perhaps reflecting the range of professional perspectives on the value of carer assessments, different approaches were being used with families across the region. Some key workers simply left the carer assessment form with families for them to complete. However, others used the carer assessment process to develop their relationship with families and improve their practice, as the following social worker explained:

With a new case it is part of saying who we are and what we do or I tend to offer it when I see a carer beginning to come under pressure as a preventative



thing... the true value is allowing the individual the chance to genuinely talk about the job that they do and how they feel about it, their needs and the future, because my experience is that carers do not get a chance, because they are busy doing... often they are burnt out... if you give someone the chance to offload they can go on for another while... and you get a very clear understanding of where that individual's at and see the unmet need emerging very clearly.

In addition to varying approaches to use of carer assessments, there was also resistance to move away from traditional care management comprehensive assessment approaches to use of the Northern Ireland Single Assessment Tool (NISAT). Some Trusts were using the carer assessment component of NISAT in adult learning disability services and others were not. There was some concern that NISAT did not offer any further improvement to existing assessment approaches:

The NISAT carer assessment is a cumbersome framework and it's on top of our existing assessment models which are perfectly good models... we don't want to introduce another set of paperwork, processes and training when it wasn't necessarily going to add a lot of value...

Several key workers also commented that the NISAT documentation was too generalised and lengthy. In addition, some felt the NISAT approach contradicted the ethos of person-centred practice in learning disability services:

NISAT was never put together for learning disabilities... we have been pushing person centred assessments and planning... proper person centred assessments are much broader and very different to a tick box document.

Interestingly, in children's services UNOCINI was the assessment model used across Trusts and there was an acceptance that carers' needs were recognised as an integral part of that process rather than requiring a separate assessment process.

Care Planning and Person-Centred Planning

Assessments and reviews were often referred to by practitioners and records of assessments were held in case files. However, there was less emphasis on care planning which is often the critical link between assessment and review processes, outlining intervention and services required. Practitioners often relied on assessments to guide reviews of services rather than building a clear care plan that could be monitored and reviewed.

Following initial or comprehensive assessments, decisions were usually made about referral to other services and/or continued key worker role. When referrals were made, it was often assumed that those organisations would undertake care planning, intervention and review. This may be straightforward for someone moving into a day care service or short break service where plans for their daily care were made and regularly reviewed. However, some young adults were using a mix of day opportunities, a range of statutory and voluntary services or no additional services. There was less emphasis on care planning for these young adults and, although key workers often made home visits or continued contacts with young adults, formal care plans or reviews were difficult to identify in case files. Most of the information about continued services for those not using day care or short breaks was recorded in contact sheets on case files. Indeed,

contact sheets revealed a lot of information about the extent of involvement between a key worker and family and, in some cases, contained the in-depth information one would expect to see in a formal care plan or review.

Person-centred planning was more commonly undertaken in children's services than adult services. In adult services, person-centred planning tended to be used in residential or day care settings rather than community services. Senior managers and key workers indicated that there was never a clear policy to use person-centred tools:

We were never told to adopt person centred planning... social workers here don't actually do it... it's incredibly time-consuming and costly.

Although formal person-centred tools were not utilised routinely by key workers in adult services, most suggested that person-centred approaches guided their thinking and their practice. It was difficult, however, to see evidence of this in case files.

I have always worked in a person centred planning way, sitting down with the individual, this is their life, this is their services... so person centred planning should be in your daily work but it's not explicit in my file, you won't find person centred planning documents... but it is clear from the contact sheets that there is a person centred approach... it is a very time-consuming model and that is fine if you have a caseload of about 5 and can sit and talk for hours.

Most professionals suggested that there were diverse interpretations of the meaning of person centred practice and how it should be applied in practice:

There's person centred planning and person-centred approaches... you get worried then that it is a dilution or the same thing painted another colour... and that is worrying because it isn't a one-off event but an integral way of working with someone and actually reflects what is happening now and what are you hoping for tomorrow.

There has been too much focus on the tools of person-centred planning whether it is a MAP or PATH or essential skills as opposed to the person-centred approach and you hear about people being person-centred planned, tick we have done that... there should be more emphasis on trying to build a person centred ethos.

Reviews

There was also variation in approach to reviews of services. For those using short break, supported living or day care services there was a standard minimum annual review and, in more complex cases, a six monthly review. For some young adults accessing a range of post-school opportunities from various providers, there were sometimes repeated reviews as each provider had their own review process. For others, the timing and process of reviews varied:

Sometimes annual reviews only happen when necessary... if the service has been in place for so long we just let it continue... but parents can initiate a review... or if something breaks down you could be reviewing 3 or 4 times a year.



It scares me sometimes because I went to a review recently and it hadn't been done in two years and there were a lot of changes, because that is how busy we are.

Due to limited staffing and pressures to conduct reviews, one manager introduced a weighting system which ensured reviews were timely but detracted from the quality of professional relationships with service users and families:

We introduced caseload weighting with annual reviews shared amongst the team. The downside of that is relationships as you had a different person coming in every year and if that person didn't have a lot of time to look at the file and learn a bit about that person, it was just a tick box exercise, but that was the reality.

Transition co-ordinators and commissioners expressed some concern about how well person-centred transition plans undertaken in children's services were reviewed in young adult life. As transition continued and changes to services occurred during the early twenties for some young adults, reviews of original decisions and plans were very important:

There seems to be a gap after children's services where PATHs that are done in schools and are not revisited again... Who maintains the support? A course can go on for three years and who has the responsibility to ensure that the next step is reached? Young people themselves talk about wanting someone to review PCPs and keep them live... there is no-one taking long-term responsibility... and not having a review can have a serious impact on health and welfare issues.

Summary

There was much variance across Trusts in relation to approaches to assessment, planning and reviewing services despite efforts to harmonise assessment models and recording styles. Person-centred planning was more commonly used in children's services rather than adult services creating a gap in the review of person-centred transition plans when young people moved into early adult life. Staff in adult services were concerned that person-centred planning was too time consuming and costly. However, there was a general view that person-centredness should be the guiding ethos of learning disability services, rather than tick box procedures. The introduction of new, lengthy assessment models was not welcomed by staff in adult services who were acutely aware of the impact of resource constraints on access to services to meet identified needs. Social workers who valued the carer assessment process viewed it as an opportunity to enhance working relationships with families and develop their understanding of the experiences and needs of carers.

3.5 Organisational, Service and Policy Context

This section reports on findings in relation to the impact of policy and organisational changes on services for disabled young people transitioning to young adult life. Issues relating to the co-ordination of services, sharing examples of good practice and priorities for the future development of services are also discussed.

3.5.1 Organisational and Policy Changes

The restructuring of teams and services under the Refrom of Public Administration was a time of major change in Trusts. The amalgamation of Trusts combined staffing, changed systems of resourcing and delivering services and meshed different working cultures. There was also a sense of loss as personnel retired or moved on:

Before RPA the children and adult disability programme were very much together and linked... Now we sit completely separate... and the management structure completely changed from the top down... We lost quite a few people that would have been very knowledgeable in learning disability... each time the structure changes there are different people managing with different visions of services.

A major challenge was the harmonisation of practice and procedures when legacy Trusts amalgamated and the varying levels of services available across the new Trust geographical areas. Many respondents indicated that the fragmentation of services across regions needed to be a priority area for the future development of services to ensure that families were not in a 'postcode lottery':

Services are not all regional so some young people have better access to some services rather than others, it is very off-putting for families... It is about postcode lottery...

However, there was also a sense of growth and positive change as opportunities for new ways of working and addressing transitions emerged, despite persistent resource pressures.

The Bamford Review was the other major policy development informing the development of learning disability services and, in particular, the focus on re-settlement from institutional care into the community. The shift from a reliance on day centre provision to a wider range of day opportunities was also grounded in the Bamford vision of social inclusion and equal lives. The Bamford Review's vision of citizenship and person-centred care was a core driver for change in Trusts and these principles were aligned with a more recent focus on personalisation and integrated service provision. Although most professionals could see post-Bamford Review progress, many respondents commented on the lack of resources available to truly implement its recommendations:

Our difficulty is that we have had Bamford for quite some time but haven't had the resources promised with it, we have our post-RPA era, trying to deliver savings...



Several managers reflected on the challenge of implementing its wide-ranging recommendations:

Bamford is too big and a lot of work could have gone into prioritising a smaller number of issues before moving onto the others... I think there were the guts of 100 actions and you cannot do them all, you end up not necessarily doing the right ones.

However, it did still seem to have currency in terms of the principles that should guide adult learning disability service development:

We are trying to Bamford proof everything we do... It certainly drives our reform and modernisation agenda and if we stick to the principles and values which are based on active citizenship, inclusion and developing person-centred approaches that should result in better outcomes for individuals.

Other broader policy documents were mentioned by some respondents, mainly because of their lack of focus on the issues facing learning disabled young people and adults. For example the physical and sensory disability strategy which paid little attention to children's issues. Children's service planning based on generic, universal approaches to service development was also criticised for failing to disaggregate the particular needs of disabled children and young people and creating a bigger gap in the transition to adult services:

All children is all well and good but I think children with disabilities struggle when they are up against children needing protection and looked after... children with disabilities are at the bottom... it is so important that we don't lose their voice and rights... we also need to be careful we don't make ledge steeper between adults and children.

There were concerns that children with specific impairment-related needs may lack access to specialist support as universal children's services treat disabled children as part of a larger homogenous group. Similarly, some professionals were worried about the marginalisation of disabled young people in the move towards localised commissioning groups basing decisions on population planning and meeting efficiency targets.

Few professionals discussed the content of the Learning Disability Service Framework or its likely impact on services, perhaps because it was in the early stages of implementation. However, policy makers and commissioners viewed it as a significant single policy document outlining service expectations and targets for the monitoring and review of services.

3.5.2 Promoting Good Practice

In each Trust, professionals could identify innovative service developments and projects. For example, the 'base' centre approach (described earlier) in one Trust area which facilitated participation in inclusive community activities. In another Trust, strategies were in place to engage with the local council, primary care services and community-based initiatives, including private and voluntary sector partnerships:

The Council has an electoral representative who is a disability champion and we are working collaboratively to... really build community capacity. We now have individuals who are outward facing in the community and having completely different lives... really deciding on what they want to do, so having a good day is not defined by us...

There was a growing emphasis on inter-sector collaboration. For example, in one Trust, strategic forums were in place under a public health framework for a joined up approach to inclusive public health initiatives. Others identified the expansion of day opportunities and supported living options as good practice developments:

There are fantastic initiatives... there is that drive back to community because it needs to be local, it has to be universal services which must be inclusive..... it is building capacity within the local community and building the capacity of the young people and their parents to feel confident.

The range of day opportunities available had been greatly enhanced by new provision by a number of voluntary and community organisations, including drama and arts based projects. Unfortunately, however, there was variation within Trusts in terms of the availability of new initiatives. For example, in one Trust, funding available in one area to support a graduate scheme for young people leaving training schemes was not available in another region of the same Trust.

We should have an agreed standard of what should be expected at transition no matter where they live and whatever their disability... This postcode lottery is just not acceptable and we need standards developed for what parents and young people should expect at transition...

There was concern that funding for transition projects tended to come from health and social care budgets rather than joined up investment from education, training and employment funding streams. Another key difficulty was the funding of services for disabled young people in transition through various programmes of care.

The pragmatic difficulty is that we're funded separately by programme of care... therefore we inevitably at transition inherit a new cost framework... so we are continually fighting the battle at transition of trying not to create anxiety for families but desperately seeking the resource to even begin to match expectations.

In addition, short-term funding arrangements for new transition initiatives hindered any long-term commitment to these new approaches to practice. The voluntary sector, in particular, emphasised the impact of uncertainty about core funding for services that families valued:

We have a very specialised service that worked very well... they will partly fund it and we have to find some charitable funding to maintain it. For some families to lose that service will be devastating... and it will be to the wire next year, whether they will they have it or not.



Projects tended to be funded on a short-term annual basis with an uncertain possibility of further funding which made it difficult to measure outcomes and progress:

We did a two year partnership project... training to staff, peer mentoring and working with families. I would like to have gone back in 5 years time to see how many of those practices are still in place. When the short-term funding finishes we don't have the luxury of doing that. In terms of outcomes I don't know if that left a legacy.

In one Trust area, a unique community development approach was established to address unmet need and promote access to universal services in the local community. However, this service ceased due to budgetary cuts. Interestingly, this community development approach still had an impact on services available in that area as some of the initiatives that had been developed were sustained by the community through volunteer and church based support. This is an excellent example of how building capacity in communities and basing services within the heart of communities has the potential for longer-term outcomes despite resource constraints:

They should never have stopped the funding... that approach was very beneficial, but there are elements of that which remain... with volunteer support... and that is fantastic because the community have a part to play in this as well.

This approach to funding community led projects that can eventually be self-sustained reflects the focus on an exit strategy for funders and commissioners.

3.5.3 Service Co-ordination and Collaboration

Improvements in service coordination and inter-agency collaboration were noted across all Trusts, including partnerships between the statutory, voluntary and private sector. Most Trusts emphasised the importance of cross-sector transition support, harnessing the resources from education, social development and housing. However, there were still areas for further improvement:

We are a health and social care organisation and why are we spending half of our day care budget on social and vocational training? There are at least two other government departments whose absolute remit that is. One of the key planks of Bamford was the mainstreaming and the rights of people with learning disabilities... For instance, we have a very well developed crisis response team in mental health who don't take people with a learning disability.

However, several key factors impacted on how well services and professionals worked together to support young adults in transition to adult life. The re-organisation of Trust and team structures had a major impact on the delivery of services in some areas. For example, the development of separate child and adult disability services allowed for more specialised services on the basis of age but created divisions in service provision at the key point of transition to adult life:

When we were working with both adults and children you were relying on both... and those relationships were all there and now they have been unpicked... that was a big change.

In the context of current reductions in spending and investment, agencies were keen to demarcate the responsibilities of service providers. This is pertinent to the provision of transition services when young adults begin to cross the boundaries of services for children and adults and the sectors of health, social care, housing, education and social development. Without joined up funding across sectors, collaborative working will be difficult to achieve. There have been examples of joint funding and strategic commissioning across Departments, for example, in relation to resettlement. However, a shift from some joint funding for targeted priority areas to a wider co-operative working culture with shared responsibility for the wellbeing of disabled people is required. The establishment of new local structures for planning and delivering services may present an opportunity to address integrated working at a local level if the needs of the local population of disabled young adults are clearly identified and prioritised.

Summary

The reform of public administration and modernisation of health and social care services in the context of a recession has had a major impact on the structure and delivery of services. There have been some positive developments in relation to increased day opportunities and innovative transition projects. However, limited investment, short-term funding arrangements, service and staff changes and limited cross-sector collaboration has hindered the development of transition support. There may be opportunities to enhance cross-departmental working arrangements as services are further reformed and local commissioning arrangements are established. However, it is important that issues affecting disabled young people in transition are prioritised within the wider agenda for child and adult policy and service development.



4. CONCLUSION AND KEY MESSAGES FOR POLICY AND PRACTICE

This research study has explored a range of transitional experiences for young learning disabled people as they move into their early adult lives. Although the focus is on the lives of ten young learning disabled adults, in discussions with professionals and the Barnardo's NI's 6th Sense Group it was clear that many of the same themes are relevant to all disabled young people in transition. A major recurring message from young disabled adults is captured in the title of this report: "Don't box me in!" The young adult participants in the study wanted opportunities to fully participate in person-centred transition plans and decisions that reflected their aspirations and helped them to reach their full potential in young adult life. However, there were major challenges for young adults and parents during the transition process reflecting both the complexity of family dynamics and the service context.

4.1 Key Messages for Policy and Practice

The thematic chapters of this report have explored transitions, post-school options, social exclusion, identities and the service and policy context. Across these themes, seven core priority areas for the development of policy and practice aimed at supporting disabled young people transitioning to young adult life can be identified. A summary of each of these priorities is presented below, including related recommendations for policy and practice.

4.1.1 Transitions and Person-Centred Planning

There are two key findings from the current study in relation to the nature of transitions to adult life. Firstly, disabled young people usually experience dual transitions from school to further education, training or employment and from child to adult health and social care services. Both transitions need to be simultaneously addressed to support a smooth transition experience for young learning disabled people and their families, including prompt referral and access to a key worker in adult services. Secondly, transition is not a one-off event as young adults leave school. Participants in this study continued to experience transitions well into their twenties and these transitions were critical to ensure continued progression towards person-centred goals for adult life. Service providers should, therefore, aim to respond to ongoing and changing transitional needs in early adult life rather than focus most transition support services on the point of leaving school.

The young adults involved in this study could be grouped into three categories in relation to transitions. Firstly, those who were still moving on and continuing to experience a range of further education courses, training and supported employment opportunities. The second group of participants experienced transitions due to difficulties with service provision rather than in response to their changing needs. For example, leaving a service because it had become more specialist or had changed its service user profile. The third group felt stuck in an established routine of service provision with few plans for further transitions. The lives of these young adults had stayed much the same since leaving school. In some cases, young adults wanted new experiences but were unsure what else they could access or how they would cope with changes to their current daily pattern of living. For others, there was a strong desire for change but there were no plans for transition in development.

Person-centred transition planning was a positive experience for young adults and their families if it was participatory, strengths-based, resulted in service outcomes and focused on high expectations of the abilities of the young adult. Person-centred transition plans should also address the holistic needs of the young person, including their emotional and identity-related needs, rather than a narrow focus on transitions from one service to another. In addition to facilitating clearer lines of communication between child and adult services, person-centred transition plans should involve co-ordinated input from the full range of providers required to meet the needs of disabled young people in transition. Such integrated planning processes should help to identify a range of sources of post-school activity and support, including mainstream, age-appropriate services.

A crucial aspect of successful person-centred transition planning that was missing for most of the participants in this study was regular monitoring and review to ensure outcomes were achieved. Person-centred transition plans undertaken in children's services or at school should be shared with adult services and held on their new social care case file. Adult services should have responsibility to review the implementation of existing person-centred transition plans in early adult life. Within adult services, this initial review of the transition plan could be undertaken by an allocated key worker or, in the absence of an allocated key worker, an adult services gateway team.

Finally, as critical transitions occur much later than the point of leaving school and continue well into young adult life, person-centred transition plans and reviews should be continued to ensure that young adults are not 'boxed in' to an inappropriate service that is not meeting their needs and that they have opportunities to continue to develop, learn and reach their full potential.

Recommendations for policy and practice

Person-centred transition planning should:

- Be participatory and strengths-based;
- Address the holistic needs of the young person rather than a narrow focus on transitions from one service to another;
- Involve co-ordinated input from the full range of relevant adult service providers and lead to service outcomes;
- Be shared with the adult services and held on their new social care case file; and
- Be regularly reviewed and updated by a key worker in adult services who is tasked with the implementation of plans in early adult life.

4.1.2 Key Worker Role and Access to Adult Services

Key workers play a major role in co-ordinating access to services, providing timely support and advocacy and encouraging continued progression in young adult life. Families value their knowledge of service systems, their signposting to sources of support and efforts they make to develop relationships with young adults and their



parents. However, some families experienced significant delays in access to a key worker or had very limited contact with their key worker. This variation in support from key workers is notable and suggests a need to clarify their role and the allocation process. In the context of high caseloads and increasing administration demands, there is also a need to prioritise the time key workers have to maintain working relationships with families and engage in direct work with young adults in transition and their parents. This could help to ensure that highly skilled and qualified social workers have the opportunity to utilise their experience and skills more effectively and undertake preventive and therapeutic work with young adults in transition and their families.

Families reported mixed experiences of social work support over their transitional years. Social workers who had made a difference in their lives had: maintained prompt and regular contact; taken time to develop relationships with them; prioritised the views young adult; signposted them to other sources of support; and advocated on their behalf. Some families were not satisfied with the level of social work support they received due to inconsistent contact; lack of follow up following a crisis in the family; and breaks in access to a social worker at key transitional times. Social workers expressed frustration about the demands of bureaucratic tasks, increasing caseloads and changing professional role.

Young adults and parents were often unsure if assessment, planning or reviews had been undertaken and copies of such documents were often missing in case files. There was much variance across Trusts in relation to approaches to assessment, planning and reviewing services despite efforts to harmonise assessment models and recording styles. Person-centred planning was more commonly used in children's services as staff in adult services were concerned that it was too time consuming and costly. However, there was a general view that person-centredness should be the guiding ethos of adult learning disability services. The introduction of new, lengthy assessment models was not welcomed by staff in adult services who were acutely aware of the impact of resource constraints on access to services to meet identified needs. However, some social workers valued the carer assessment process as an opportunity to enhance working relationships with families and develop their understanding of the experiences and needs of carers.

Although direct payments had been introduced since the previous study, knowledge of direct payments was limited and uptake was reported to be slow, particularly since a recent judicial review decision which has led to a lack of clarity about capacity issues linked to the use of direct payments. There was variability in the type of short break provision available within and across Trust areas. All participants in this study who used short breaks as children were able to access short break services as young adults. However, some experienced delays in access to these services, could only use short breaks for shorter periods or felt that adult short break provision was not tailored to the needs and interests of young adults. Further attention could be paid to the provision of age appropriate short breaks for young disabled adults which may involve a shift towards more community-based provision rather than a reliance on traditional residential care for adults with a broad range of ages and needs.

None of the study participants had experienced supported living as they were all still living at home with their parents. Young adults and parents had very limited knowledge of supported living options and generally assumed that these were not available.

Further development of supported living programmes is required to enable young learning disabled adults to fulfil aspirations to live independently or with support in the community.

Recommendations for policy and practice

An audit of short break and supported living opportunities for young learning disabled adults should be undertaken to review the extent of provision and projected need for further service development. Key workers in adult services should:

- Be promptly identified before the cessation of support from children's services to avoid gaps in support and ensure timely referrals to relevant adult services;
- Have a clearly identified role in relation to supporting young disabled adults coming into the adult service system;
- Undertake person-centred assessments which lead to care plans that can be regularly reviewed and updated;
- Have dedicated time for direct and therapeutic work with young adults in transition and their parents; and
- Have access to training and guidance on capacity issues and use of direct payments.

4.1.3 Supporting Parents in Transition

Findings from the study indicate that parents are also in a stage of transition as their sons/daughter move through young adult life. Parents are faced with new challenges as their sons/daughters become increasingly independent, engage in personal relationships and express a desire for change in their adult lives. In many cases, parents were undertaking continued caring roles despite their own health care needs. Parents also had fears and anxieties about the future for their son/daughter but few had made concrete arrangements to prepare for future transitions. Given these findings, the variable application of carer assessment processes across Trusts is significant. The importance of timely carer assessments with service outcomes that support carers of disabled adults should be emphasised in policy guidance and staff training.

Some parents had very positive and enabling attitudes that encouraged inter-dependent relationships and facilitated further growth and development for their son/daughter. Other parents were reluctant for their son/daughter to leave home and envisaged a future of continued mutual dependency. These parents were mainly guided by their concern to protect their son/daughter from exploitation or manipulation due to their perceived vulnerability. However, over-protective parent and professional decision making had the potential to diminish post-school opportunities for further education and employment, personal relationships and social inclusion. Professionals need clear guidance on the how the rights of young, learning disabled adults can inform their practice and how to promote measured risk-taking, based on balanced and robust risk assessment processes that are regularly reviewed to reflect changing strengths and needs. Such assessment processes could harness the existing awareness of many young



adults about their own vulnerability and the need for strategies to keep themselves safe. These improvements in risk assessment practice may also help to inform parental decisions and encourage parents to facilitate their son/daughter's access to more post-school opportunities.

Recommendations for policy and practice

Adult disability service providers should:

- Utilise carer assessment processes to pay greater attention to the social, emotional and health care needs of carers of young disabled adults, particularly at transition points;
- Support parents to make plans for future transitions and encourage inter-dependence for their son/daughter;
- Have access to training and guidance on strengths-based and person-centred models of risk assessment to ensure risks are carefully balanced with the rights of young disabled adults; and
- Have knowledge and skills of family systems to enable them to sensitively and effectively negotiate power dynamics within families and address the needs and rights of both young disabled adults and their carers.

4.1.4 Participation and Advocacy

Despite increasing emphasis on the participation of disabled service users (children and adults) in decisions affecting their lives, there is still a heavy reliance on parents as proxy decision-makers, particularly in relation to post-school opportunities. Young adults were often presented with limited choices or only involved when final decisions were already made by parents or professionals acting with their best interests in mind. In order to ensure, post-school activities reflect the true interests and needs of young learning disabled adults their voice must be heard and opportunities for self-determined or supported decision making should be a key element of transition planning processes. Improved access to information about service options and rights and access to independent advocacy and peer support may help to develop the confidence and skills of young adults to express their views, challenge the opinions of others and contribute to decisions affecting their lives. Whilst there is general agreement that disabled young people should participate in decisions affecting their post-school lives, practitioners need training and guidance on how to promote the participation rights of young adult whilst working with their parents and addressing complex family systems.

Recommendations for policy and practice

There is a critical need to address the participation rights of young disabled adults at a range of levels including:

- Targeted funding and capacity building to support the development of young adult participation groups and a peer support network;

- Access to information and independent advocacy to ensure the voice of young disabled adults is prioritised;
- Training on alternative and creative approaches to transition planning that can facilitate the involvement of disabled young people who use varied methods of communication;
- Awareness raising of the rights of disabled adults for service providers, parents and disabled young people themselves; and
- Increased opportunity for disabled young people to experience participation and develop the confidence and skills to participate from an early age.

4.1.5 Social Inclusion

Social inclusion was a top priority for all participants in the study as young, learning disabled adults continue to experience high levels of social isolation and exclusion from opportunities to engage in relationships with peers in inclusive social activities. There is also a need to address young disabled people's experiences of discrimination and abuse in a range of settings, including raising awareness of disability rights, developing effective safety strategies and providing therapeutic support for those who have experienced disabling and abusive situations.

Greater efforts to address unequal opportunities for disabled young adults to access a full range of mainstream, universal social and leisure opportunities are also required. This is particularly important as opportunities for social activity and interaction help to develop the self-esteem, confidence and participation skills of disabled young people which have a direct impact on their capacity to have a say in decisions affecting their lives and the extent of informal sources of support.

Recommendations for policy and practice

A cross-sectoral response to addressing the social exclusion of disabled young adults is required which should include:

- Policy and guidance across sectors to clearly indicate the responsibility of various departments and agencies for nurturing and facilitating social relationships;
- The development of inclusive mainstream social and leisure opportunities that actively engage disabled young people in their local communities;
- Targeted programmes in schools and further education, training and employment services to encourage the establishment of sustainable social networks;
- Incorporating social needs into person-centred transition assessments, plans and reviews to ensure need is captured and a service response is facilitated; and
- Recognition of the extent of bullying and abuse experienced by young disabled adults in transition and clear policies and procedures on how best to address discrimination and violence at multiple levels of society.



4.1.6 Emotional Wellbeing and Identity

The transition from teenage years to young adult life is a life stage when experiences of impairment and disability can impact on the construction of self-identity. Lack of access to information about impairment and disability rights, inappropriate post-school placements and limited opportunities for peer support can negatively impact on the emotional wellbeing of disabled young adults. Many of the young adults in the study highlighted issues relating to low self-esteem, and depression or anxiety often linked to experiences of disablism, social exclusion and familial issues. However, few had the opportunity to address their emotional needs in a safe and supportive context. Social workers could play a greater role in meeting the emotional, identity-related needs of disabled young people in transition as part of their key worker role.

Recommendations for policy and practice

In order to more adequately address the emotional wellbeing of disabled young adults there should be:

- Targeted public health services aimed at promoting the emotional wellbeing of disabled young people;
- Opportunities in schools and further education, training and employment to address issues of self-confidence, identity and self-esteem;
- Inclusion of identity-related needs and emotional wellbeing in assessments, plans and reviews of health and social care services, including opportunities to explore experiences of impairment and disability;
- Recognition of the impact of discrimination and abuse on the emotional wellbeing of young disabled adults in transition and therapeutic services to address related needs;
- Peer support and advocacy for young adults to challenge disabling encounters and assert their rights in varying contexts; and
- Increased opportunities for affirmation and participation to build the resilience and capacity of young disabled adults to exercise their rights and make a valued contribution to society.

4.1.7 Developing Post-School Options

The recent shift towards more flexible day opportunities is a very positive step forward however the continued development of a greater range of post-school options is critical to address transitional needs. There are concerns about disabled school leavers who are falling between gaps in services and are inappropriately placed in either day centres or day opportunities. The range of available college courses linked to supported employment opportunities also needs expansion to avoid repetition and further opportunity for continued education, learning or progression to employment. It is important that service providers and parents aim beyond a baseline of adequate care or daily activity towards a great fulfilment of the aspirations of young disabled adults. Monitoring educational outcomes and progression is crucial to ensure progress through further education and training opportunities.

Recommendations for policy and practice

In order to develop the range of post-school opportunities for young disabled adults there should be:

- Longer-term investment to expand age appropriate day opportunities that meet person-centred needs, challenge young adults to continue to reach their full potential, and are community-based;
- Stepped service models that address gaps in provision for those who are not suitable for day care and not ready for day opportunities;
- Opportunities for inclusion in mainstream further education, training and employment programmes with necessary adaptations and support in place;
- A review of day opportunities and supported employment options to ensure equality of opportunity for young disabled adults with personal care or mobility needs and expansion of services that can accommodate such needs; and
- Close tracking and monitoring of the outcomes of participation in further education, training and employment to avoid repetition and ensure the continued progression for young disabled adults.

4.2 Conclusion

Given the lack of extant research in this area, it is intended that these findings contribute to our understanding of the transitional experiences of young learning adults and inform current policy and service developments in this area. Addressing the needs of young learning disabled adults, and the wider population of disabled people, is the responsibility of all service sectors and demands a co-ordinated, multi-agency, cross-departmental approach at policy and practice levels. The findings from this study also highlight the need for closer monitoring of services, timely evaluation of new initiatives and sharing of good practice across Northern Ireland. Finally, at a wider level of societal change, there is a need for continued awareness-raising of disability rights and challenges to discrimination and the unequal opportunities experienced by many young disabled adults in our communities.



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APPENDIX 1: Transition Arrangements in Health and Social Care Trusts

Trust	Transition co-ordinators	Transition arrangements
TRUST A	None	<ul style="list-style-type: none"> • A social worker from adult services links with school to collate a transition file on young people due to turn 18 the following year and attends school reviews • Pending cases are allocated to a key worker for initial assessment. • Close links are maintained with the ELB and annual meetings are held with schools to plan for school leavers • An annual parent evening is also held in school to share information about services available.
TRUST B	Transition Co-ordinator: <ul style="list-style-type: none"> • Based in children's services • Working with young people 14-19 yrs • On leave and no funding for temporary cover 	<ul style="list-style-type: none"> • Transition co-ordinator works with schools and other organisations to plan transitions • Tends to focus on young people moving into day opportunities such as college or supported employment • Some cases not accessing transition co-ordinator services were only known to adult team when they turned 18 yrs • Planning a new system where Team Leaders are informed about pending cases at early transition points 14-16yrs
TRUST C	None	<ul style="list-style-type: none"> • Team Leaders for adult and child services attend school reviews for cases approaching transition • Team Leaders work closely with schools and Education Transition co-ordinators to plan for the cohort due to leave the following year • Cases are allocated to a child and adult key worker who should co-work until child moves into adult services • Would like to plan earlier, particularly for more complex cases requiring intensive/ specialist support as young adults
TRUST D	Transition Co-ordinator: <ul style="list-style-type: none"> • Based in children's services • Working with young people up to 25 yrs 	<ul style="list-style-type: none"> • Transition co-ordinator works with schools, other organisations, colleges and the adult team at an early stage • Attends school reviews aiming to plan transitions • Maintains a consistent contact for families until transition is complete and/or they are allocated a key worker in adult services.



APPENDIX 2: Summary Profiles of Young Adult Participants

Robbie was 20 years old and still lived at home with his parents and siblings. He had enjoyed his school experiences and stayed in the same mainstream primary school (which had a special unit) until he was 11 when he moved to a local mainstream high school with a learning support unit. Robbie stayed in secondary school until he was 17 years old. Although he had contact with a transition worker, Robbie experienced many breaks in contact from social services due to staff changes. When he left school he studied college courses before securing a place on an employment based training programme. This placement will last for two years. He also undertakes unpaid work for a half day in a local shop. Robbie continues to use a family-based short break one evening per week and still has two evening visits per week with a domiciliary carer. He likes films, using his computer, swimming and listening to music.

Natalie was 21 years old and still lived at home with her parent and siblings. Since the first study her parents had divorced and she had experienced a series of family bereavements. Natalie enjoyed attending a mainstream primary school and secondary school (with a special unit) until she was 17 years old. Natalie and her mother had limited contact with social services when they experienced a crisis or requested support but felt that they did not receive any follow up care. They undertook transition planning themselves with support from the school when Natalie turned 16 years. She attended a training for employment scheme for four years and then secured a one-day work placement. She is due to start a new three year training and supported employment programme which she hopes will lead to paid employment. Natalie likes watching television and the Special Olympics.

Laura was 24 years old and still lived with her parents and siblings. She had also experienced a series of bereavements since the first study. Laura and her family had been allocated to a range of key workers over the years. Support was minimal at times however, she felt well supported by her current social worker. Laura stayed at the same special school for primary and secondary level education until she was 19 years. Transition planning began when she was 16 however due to a lack of accessible post-school options, she was forced to rely on services from a training and resource centre. She also participated in two evening college courses and a three week work placement. Laura does not enjoy the centre and wants to pursue further employment opportunities. She recently started to attend a community-based centre one day per week which she really enjoys. Laura's children's short break service ended when she was 18 years and she waited almost one year to access a new short break facility due to a lack of accessible services. Laura does not enjoy the adult short break service as most people there are much older than her. She also receives daily support from personal carers in the family home. Laura enjoys music and going on social outings with her family members.

Maurice was 20 years old and still lived at home with his parents but his siblings had moved away. He moved from a mainstream to a special primary school and then a special secondary school until he was 19 years old. Transition planning began in his final year at school and he moved from school to a life skills college course. He does not like college classes but does enjoy socialising with other people at college. He had a few short-term work placements however none of these have led to continued employment

experience. Maurice's children's residential short break service ended when he reached 18 and moved to an adult residential short break facility. He had overnight stays of at least two nights per month but did not enjoy staying there. He continued to avail of domiciliary support services. His carers have changed over the years but he has had the same carer for the past six years and really enjoys their weekly social outings. Maurice and his parents have also been allocated to various social work staff but have been mostly satisfied with their support. Maurice enjoys using his computer, listening to music and watching movies.

Joanne was 24 years old and still lived at home with her mother but her siblings had moved out. She had moved from a mainstream primary school to a special secondary school. When she was 16 years she moved to another special school and stayed there until she was 19 years old. Joanne did not receive any support to plan for her transition from school. On leaving school, she began two college courses and then attended a range of day opportunities including a training and resource centre, college and a drama-based group. Joanne also has a part-time job which she really enjoys. Joanne continued to use domiciliary support and had six different carers who provided eight hours of care per week. They supported Joanne to access social activities and evening classes such as art or drama. Her mother managed direct payments to help organise this range of support. Joanne and her mother experienced a series of changes in social work staff with some gaps in provision during her secondary school years. However, they were very happy with their current social worker and the level of support they received. Joanne enjoys listening to music and has a passion for story writing.

Sarah was 22 years old and still lived at home with her mother but her siblings had moved out. She lived in a new home adapted to meet her access needs. Her family-based short break service had ceased when she was fifteen due to her increased support needs. However, she still used the same residential short break facility one week in nine and her sister provided short break support one day per week. Sarah attended the same special school until she was 19 years old. Although transition planning was undertaken whilst she was still at school, the only post-school option was day care and no places were available so Sarah spent ten months being cared for full-time by her mother at home until a two day placement was eventually provided in the local day care centre. She waited another nine months for a three day placement and a further nine months for a five day placement. During this time her mother was forced to cease employment to undertake her caring role for Sarah. She has mostly had the same social worker since she was a child who provided a range of support over the years. Sarah enjoys playing on her trampoline and watching DVDs and television.

Callum was 22 years old and still lived at home with his parents and siblings. Callum's father was the main carer as his mother had returned to work when he was a teenager. Callum attended a special primary and secondary school until he was almost 19 years old. He had support from a transition officer who developed a five year transition plan involving a planned move to a full-time day centre placement. However, only a two day placement became available. Later, Callum attended a music and arts-based group two days per week which he enjoyed. Callum plans to stop attending the centre and join another drama based group which also offers college courses. Since he was 19 years old, Callum enjoyed a family-based short break two nights per month. He had also recently begun to use a residential short break facility for five days every three months. Callum's family had very limited support from social services over the years. They



requested support when he was 17 years old but were not allocated to a new keyworker until he was 19 years old. Callum's family are very happy with his current key worker but were dissatisfied by the poor response to their request for support and the waiting time for a new keyworker at a critical time of transition. Callum likes action movies and computer games.

Edel was 26 years old and still lived at home with her parents and siblings. She attended a special school for her primary and secondary education until she was 17 years old. On leaving school, Edel completed a computing course at a local community centre and then stayed at home full-time. Her parents felt that her post-school opportunities were limited as she did not fit into mainstream or specialist further education or employment opportunities. Edel and her family are still supported by the same social worker although they experienced a change in personnel during the transition from school. Edel accessed fortnightly befriending services however, this ceased following staff changes. Edel likes animals and enjoys going to the cinema.

Lorraine was 26 years old and still lived at home with her mother and siblings. She attended a mainstream high school (in a class for students with special educational needs). On leaving school at 16 years old, Lorraine accessed job link services which involved retail training at college and work placements. Lorraine struggled to cope with the demands of this programme and moved to a supported training and employment service. After several unsuccessful work placements she volunteered in a local supermarket which, after almost two years, became a paid part-time position with support from a job coach. Lorraine and her family did not have a lot of contact from social services over the years apart from a referral to a befriending service which she accessed briefly during her teenage years. When she turned 18 years, following a proposal from the adult services team, the family agreed for her case to be closed. Lorraine enjoys watching television, shopping and using the computer.

Ronan was 29 years old and still lived at home with his parents but his siblings had moved out. Ronan stayed at the same special school until he was 19 and then moved to a three day placement in day care and a two day college placement. When he was preparing to leave school, a supported employment placement was considered but Ronan refused to attend. Ronan still has this same routine of day care and college ten years on. He does not enjoy repeating the same college courses but does enjoy the opportunity to meet friends there and has learnt how to travel by bus to college independently. Ronan has also worked in a local supermarket one evening per week since he was 16 years old and really enjoys this opportunity to engage with the local community. Ronan and his family had a range of social workers over the years but have limited contact with their current social worker. When he was a teenager, Ronan used a residential short break service and a family-based short break service. However, he had a two year period with no short breaks because the only adult services placement offered was far from his home. He recently began to use a residential short break facility closer to his home. Ronan enjoys social outings, football games and country music.

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