DON’T BOX ME IN!

Disability, Identity and Transitions to Young Adult Life

EXECUTIVE SUMMARY

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1. INTRODUCTION

This report is an executive summary of the findings of a follow-up study on the transitional experiences of ten young learning disabled adults who, as children, had participated in a family support study ten years previously (Kelly, 2003, 2005, 2007). An overview of the background to the study and methodological approach is presented followed by a summary of the key research findings under seven main themes: transitions and person-centred planning; key worker role and access to adult services; supporting parents in transition; participation and advocacy; social exclusion; emotional wellbeing and identity; and post-school options. Recommendations for the future development of policy and practice are also provided for each of these themes.

1.1 Background to the Study

This report is based on a follow-up study of ten young learning disabled adults who participated in a study 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 learning 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 is 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 age inappropriate post-school options (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 and this is the 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.
primary focus of the current study. 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 health and social care policy 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.

At a global disability policy level, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), ratified in the UK in 2009, urged state parties to ensure that disabled people have access to further education, training and employment on an equal basis with others, opportunity to live independently and experience of full community inclusion and participation (UNCRPD, 2006). At the local disability policy level, the Carers and Direct Payments (NI) Act (2002) and Autism Act (NI) (2011) aimed to enhance provision for carers and people with autism and promote service user and carer control of services. Strategically, the Bamford Review (2002-2007) of mental health and learning disability law, policy and provision was also a major policy development in Northern Ireland. Its recommendations for re-settlement from hospital into the community, stepped care models and person-centred planning are now well integrated into more recent health and social care policies (Bamford Review, 2005).

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).

Three strategic disability policy documents recently issued also have relevance to transitions to adult life: the Disability Strategy 2012-2015; the Learning Disability Service Framework 2012-2015; and the Physical and Sensory Disability Strategy 2011-2015. 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). 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).

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) which aimed to improve outcomes for all children and young people over a ten year period. The strategy identified six high level outcomes for children and young people that continue to influence current policy and practice developments: being 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 plans identify key outcomes in relation to disabled people including: improved support to live in the community and increased opportunities for training and supported employment.

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); and later the cross-sector, multi-agency Children and Young People’s Strategic Partnership (CYPSP) to focus on improving outcomes for children and young people in Northern Ireland including disabled young people in transition. The CYPSP’s transition action plan highlighted early transition planning alongside the need for continued access to services as children move into adult services (CYPSP, 2011). The development of passports and integrated, multi-agency, person-centred plans is recommended to improve the experience of transition to adult services for disabled young people and their families. 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. Further opportunities to access peer mentoring programmes to inform young people of their rights and encourage them to participate in decisions affecting their lives were also recommended.
There have also been developments in education policy relating to transition. The Special Educational Needs and Disability (Northern Ireland) Order (2005) (SENDO) and associated Education (Special Educational Needs) Regulations (NI) (2005) make provision for: transition planning at the stage of a young person’s 14th birthday and the sharing of information between education and health and social care. The importance of inter-agency working and involving disabled young people in assessment and review processes is also emphasised.

Despite this changing legislative and policy context across disability, child care and education sectors, concerns about provision for disabled young people in transition have persisted alongside continuing evidence that they are at higher risk of poorer post-school outcomes (Horgan et al., 2010; McIlwhan et al., 2009; UN, 2007). Unfortunately, several government and independent research reports 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 (ECNI, 2012; Haydon, 2008; Jones et al., 2007; McMahon and Keenan, 2008; Mencap, 2007; Monteith et al., 2009; NICCY, 2010; OFMDFM, 2009). In the context of growing living costs, recession and welfare reform, there are fears that the review of health and social care services and the personalisation agenda will lead to further efficiency savings and the retrenchment of statutory support for disabled people (Lundy et al., 2012). The struggle for targeted and protected budgets for disabled young people in transition may become even more challenging (CDSA, 2012). 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 the transitional and early adult life experiences of young learning disabled adults using a mainly qualitative approach incorporating case file reading, semi-structured interviews and biographical narrative techniques (Denzin & Lincoln, 2000). 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). 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. A visual life story book and photographs were utilised to support interviews with young adults and explore their journey to young adult life. The researcher also read their social care case file, with prior consent, to gather documentary information about services used over the past decade.

The study was approved by the Office of Research Ethics Committees Northern Ireland (ORECNI). A professional advisory group and a young adult advisory group guided the conduct of the study. The young adult advisory group also assisted with the identification of themes emerging during data analysis and the development of a DVD to disseminate the findings of the study.
3. FINDINGS

Seven core themes emerged from the study as priority areas for the development of policy and practice aimed at supporting disabled young people transitioning to young adult life: transitions and person-centred planning; key worker role and adult services; supporting parents in transition; participation and advocacy; social exclusion; emotional wellbeing and identity; and post-school options.

3.1 Transitions and Person-Centred Planning

Each of the four Health and Social Care Trusts involved in the study had their own transition arrangements. 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 usually based these posts within children’s services. Their roles varied and, although they often undertook person-centred transition planning, their involvement did not extend into young adult life or have a direct impact on the provision of adult services.

There are two key findings from the current study in relation to the nature of transitions to adult life. Firstly, disabled young people 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 when 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.
Young people and their families want a smooth referral to a key worker in adult services, person-centred transition planning that is connected to available adult services, and reduced waiting times for information about eligibility for access to adult services. 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. This demands 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. 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.

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 social care case file. Adult services should have responsibility to review their implementation in early adult life. 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. As critical transitions occur much later than the point of leaving school, person-centred plans and reviews should also be continued to ensure that young adults are not ‘boxed in’ to an inappropriate service that is not meeting their needs and 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 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.
3.2 Key Worker Role and 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. All participants, except one, had a named key worker in adult services from the social work profession. Families valued their knowledge of service systems and signposting to sources of support. However, some families experienced significant delays in access to a key worker or had very limited contact with their key worker. This variation in key worker support 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. However, 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, only two parents in the study used this form of support. Other parents had no knowledge of direct payments or were concerned that they could not identify a service provider or cope with the demands of managing direct payments. Professionals emphasised that there had been a decline in use of direct payments following 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.
3.3 Supporting Parents in Transition

Findings from the study indicate that parents are also in a stage of transition as their sons/daughters move through young adult life. There are major changes and challenges for parents as they adapt their role and promote their son/daughter's growing independence and life choices. 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. Parents were mainly guided by their concern to protect their son/daughter from exploitation or manipulation due to their perceived vulnerability. However, overprotective 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.

Many parents continued with their caring roles 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 heavily on their parents. 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 prepare them for future transitions.

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 interdependence 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.
3.4 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 that 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 alongside 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, key barriers to their involvement were identified including a need to: develop more creative ways for prioritising the voice of disabled young people; building their capacity to have a say through involvement in everyday decisions and early experience of participation; encouragement for disabled young people to feel empowered to challenge service providers and parents; and guidance for parents and professionals on higher participation expectations, adult participation rights and negotiating complex family dynamics.

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 disability 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.
3.5 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. Opportunities for developing social relationships were restricted for a range of reasons including: limited access to inclusive, mainstream social activities; loss of social networks as service settings changed; and parental concerns about risk and vulnerability. Participants who were engaged in social and leisure opportunities often only accessed provision for disabled people and were heavily supported by their parents.

Half of the participants had direct experiences of bullying or abuse in a range of settings including school, college, housing estates and social groups. 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 also be provided for disabled young people 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 is 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 availability 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.

3.6 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. Young adult perceptions of disability, impairment and self-identity were often related to post-school experiences and use of services. 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. 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 programmes 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 provision of therapeutic services to address related needs;
- Peer support and advocacy for young disabled adults to challenge disabling encounters and assert their rights in varying contexts; and
3.7 Post-School Options
There has been an expansion of day opportunities to promote social inclusion and relieve pressures on day centre services which are focused on provision for those with more complex needs. However, there is still a need to further develop the range of day opportunities available across the region and to monitor the outcomes for young disabled adults. There are concerns about two groups of disabled school leavers who are falling between gaps in services: those inappropriately placed in day centres due to personal care needs; and those who are not ready to cope with mainstream day opportunities but would be unsuitably placed in day centres. There is a need for a stepped service model for these groups of young adults to ensure they are supported to engage in day opportunities and mainstream social and leisure services rather than becoming stuck in inappropriate services or remaining at home with no social outlets.

Seven of the young adults in the study accessed college courses on leaving school, most commonly in segregated classes for disabled young people. While some described feeling very happy at college, others felt unsupported and struggled during their early days at college. 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 the same courses. 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.

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.

College courses that were directly linked to training for employment or work experience were deemed to be the most successful. Four out of the ten young adults enjoyed training and employment opportunities. Short-term work placements were valued by participants but did not usually lead to longer-term progression into employment. Most young adult participants were keen to pursue employment in the future 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. 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 that would challenge young disabled adults to learn employability skills.
in a supportive environment. Success stories from employers of young disabled adults 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.

**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. CONCLUSION

This study explored the transitional experiences of young learning disabled people as they moved into their early adult lives. Although the focus was on the lives of ten young learning disabled adults, in discussions with professionals and the Barnardo’s NI Sixth Sense Group it was clear that many of the same themes are relevant to a range of 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 affecting their post-school lives; and opportunities 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.

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 inadequate cross-sector collaboration has hindered the development of transitional supports. 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. There may be opportunities to enhance inter-agency working arrangements as services are further reformed as part of the implementation of the ‘Transforming Your Care’ report and the ongoing work of local commissioning groups. 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. 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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An audio accessible version of the findings of this research is available by request to the author at:

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