

Children's Rights

NICCY

northern ireland commissioner
for children and young people



Review of Transitions to Adult Services for Young People with Learning Disabilities

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The views expressed herein are those of the authors.

Foreword



As the Northern Ireland Commissioner for Children and Young People (NICCY) it is my primary aim, as set out in legislation, 'to promote and safeguard the rights and best interests of children and young people'. The United Nations Convention on the Rights of the Child, upon which I base all my work, states that Government must recognise that children with disabilities 'should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.'

I am greatly concerned that since NICCY was established in 2003 the office has regularly received reports that the rights and best interests of disabled children are not being properly protected in Northern Ireland. The effectiveness of arrangements to support the transition of young people with learning disabilities from children's to adult services has been a particularly recurrent theme in concerns reported to NICCY.

While I acknowledge that attempts have been made to alleviate some of the difficulties faced by children and their families when transitioning to adult services, I am concerned that the enduring nature of barriers to the full realisation of children's rights in this area requires a fundamental reconsideration of current transition arrangements.

Central to my role in safeguarding children's rights is my statutory duty to keep under review the adequacy and effectiveness of the law, policy and services relating to the rights and welfare of children and young people. In order to examine the area of transitions more fully I commissioned Queen's University Belfast to conduct a scoping exercise on transition arrangements for young people with learning disabilities in relation to education, training, employment, health and social care.

A key aim of the exercise was to consider if cases reported to my office were indicative of broader structural deficits in law, policy and practice relating to transitions processes.

The authors have provided a critical analysis that identifies a range of inconsistencies, weaknesses and gaps in existing arrangements. The report demonstrates that many of these concerns are not new - they reflect issues that have been debated and documented over a number of years but have ultimately remained resistant to change.

Most importantly, the report uses the United Nations Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities as the framework to consider transition arrangements, often highlighting the stark contrast between the international obligations placed upon Government and the reality that is experienced by young people and families, as well as professionals seeking to support them.

The scoping exercise has identified many areas where the arrangements for transition and the provision and supports offered to young people before, during and after transition should be improved. In considering and reflecting upon this report I have been reminded time and again of the need for Government to ensure that there is a sound statutory basis for young people's transition to adult services in order to effectively address these concerns.

In taking forward this work my office will be asking the Northern Ireland Executive to revisit the duties currently placed on departments and statutory bodies to ensure that the transitions planning process is fully integrated, that there is effective cooperation between agencies and that the views of young people themselves are properly taken account of.

I would like to give particular acknowledgement to those who shared their insights and experiences with the researchers during this project.

I commend this report to you and I call on the Northern Ireland Executive to now carefully consider how arrangements can be strengthened in order to further realise the rights of all young people with learning disabilities throughout their transition to adult services across Northern Ireland.



Patricia Lewsley-Mooney
Northern Ireland Commissioner for Children and Young People
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Contents

Foreword	1
Executive Summary	4
1. Introduction	11
1.1 International Human Rights Framework	11
1.2 Learning Disability	17
1.3 Transitions	19
1.4 The Northern Ireland Policy Context	20
2. Education, Employment and Training	24
2.1 Transitions Planning in Education	24
2.2 Access to Effective Education and Training on Leaving School	29
2.3 Employment	32
3. Health and Social Care	36
3.1 Social Care	36
3.2 Health Care	45
3.3 Support for Families and Carers	51
4. Social Security, Leisure and Transport	54
4.1 Social Security	54
4.2 Leisure	56
4.3 Transport	59
5. Summary and Conclusions	62
5.1 Integrated Planning	62
5.2 Person-Centred Planning	63
5.3 Consistency in Provision across Northern Ireland	63
5.4 Access to Information	64
5.5 Participation of Young People in Decision-Making	64
5.6 Recommendations	65
Appendix: Learning Disability Schools in Northern Ireland by Type, ELB and Leaving Age	68
References	71

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Executive Summary

This report into transitions to adult services for young people with learning disabilities has been conducted on behalf of the Northern Ireland Commissioner for Children and Young People (NICCY). The remit of the project was to provide a critical analysis of transitions to adult services for young people with learning disabilities in Northern Ireland (NI) in the context of: education; employment and training; and health and social care. While the areas of social security, and leisure and transport were not included in NICCY's original terms of reference for the study, these were identified as important by the research team during the course of the project. In particular, the inclusion of these areas is reflective of the interdependent, indivisible and holistic nature of children's rights more generally.

The report is underpinned by a children's rights-based approach. In particular, the project sought to investigate compliance with international child rights standards and employ processes which themselves comply with international standards on children's rights, with a particular focus on the rights of young people with learning disabilities under the United Nations Convention on the Rights of the Child (CRC) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The project consisted of: an analysis of children's rights standards in the context of the study; a review of legislation, policy and literature; and discussions with a variety of stakeholders across each of the thematic areas. The latter were not formal interviews and what was discussed is not therefore represented as data in the report. Instead, we took the opportunity to talk to Education and Library Board and Health and Social Care Trust officials, employees of Mencap, and the post-19 lobby group, principals of both Severe Learning Disability (SLD) and Moderate Learning Disability (MLD) schools, and parents and young people with learning disabilities attending both special and mainstream schools. We also attended meetings of the Children and Young People's Strategic Partnership's sub groups on children with disabilities and on transition and are very grateful to them for sharing information with us. In each instance, we were given further insight into the key issues affecting young people with learning difficulties on transition.

Transitions to adult services for young people with learning disabilities have long been identified as a particular issue and there is a clear history of attempts to address the associated difficulties through a range of both government and NGO based initiatives. Nonetheless, young people with learning disabilities continue to encounter significant difficulties on transition from school and from child to adult health and social care.

Key concerns can be summarised as follows:

Education, Employment and Training

The existing statutory duty to plan for transition is currently only available to young people who have statements of special educational need. The availability and adequacy of transition planning, support and post-school options varies across Education and Library Boards (ELBs) and Health and Social Care Trusts (HSCTs). Moreover, there continues to be variation at the age in which a young person has to leave a Moderate Learning Disability (MLD) school in contrast with those attending Severe Learning Disability (SLD) schools. Young people with learning disabilities and their families do not always receive appropriate information about the options and support available to them on leaving school. Nor is there a statutory obligation on a public body to take young people's views into account in decision making processes. This is compounded by the inadequacy of joint/interagency working between staff in education and health and social care services and between the public and voluntary sectors. It is not yet clear how the Review of Special Educational Needs and Inclusion proposals, which are still in development, will impact on the transitions process for young people with learning disabilities. However, there is concern that there will be a reduction in provision and in statutory protection for children who, as defined under the new proposals, would no longer have statements of special educational needs. There is also concern at the current lack of statutory obligations surrounding the transitions process for young people who do not have statements.

For young people with learning disabilities attending Further Education (FE) courses, concerns centred on the lack of support for the young person when settling into FE and the lack of genuine options and subsequent opportunities for progression when a course comes to an end. There are no specific statutory obligations to support young people with learning disabilities on transition into FE and from FE into employment. In the context of employment, again there is variation across NI in terms of supported employment opportunities, the availability of suitable work experience placements, and the impact of part-time working on social security benefits.

Health and Social Care

The availability of age appropriate and flexible day care and short break services are limited and vary across Health and Social Care Trusts. Parents and young people do not always have access to accurate and/or detailed information on the real options available, including information on the range of accommodation and services, alternative sources of support, and on the eligibility/entitlement for services including direct payments and carers assessments.

Young people with learning disabilities are much more likely to experience mental health problems. Concern has been expressed at the potential negative impact of transitions on the mental health and wellbeing of young people with learning disabilities as they adjust to unfamiliar environments. There is a need for support and information for young people making transitions to adult mental health services, in and out of acute hospital care, and in relation to sexuality and relationships education. Concern has also been expressed at the reduced levels of access to allied health care services on leaving school, associated delays and unclear eligibility and referral criteria in accessing such services. These issues are exacerbated across Health and Social Care Trusts since not all currently have Transition Officers.

Families of young people with learning disabilities provide care and support well beyond what is normally expected and over a longer period of time. However, the practical and emotional support provided to families, particularly at times of transition, is fragmented and patchy across Northern Ireland.

Social Security, Leisure and Transport

Uncertainty around the impact and complexity of the proposed welfare reforms is an added source of stress for families. The issues highlighted above are compounded by the lack of suitable transport arrangements and independent travel initiatives, particularly for young people living in rural areas. Nor do young people with learning disabilities have equal access to age-appropriate leisure opportunities on the same basis as rest of their peers. The latter becomes particularly pertinent when young people leave the security of school-based social networks, often outside their own communities.

In addition, there are significant, cross-cutting issues:

Integrated planning

The Committee on the Rights of the Child has emphasised the need for appropriate co-ordination of services for children with disabilities to ensure that their needs are addressed effectively (UN 2006, at para 7). There is a need for an integrated planning service between education and health and social care. While there have been efforts to improve communication and co-operation between education and health and social care, there are, in effect, two separate planning and delivery processes for transition which often occur at different points in time in a young person's life.

Person centred planning

Article 3 of the CRC requires children's best interests to be a primary consideration in all matters affecting them. There is a need for person centred planning across the transitions processes. There is a clear sense that decisions about education, employment, and health and social care are often determined by what is available rather than what is in the best interests of the young person and there is little evidence that they get support to ensure their voice is heard.

Consistency in provision across Northern Ireland

Article 2 of the CRC requires provision to be made for all young people with disabilities without discrimination. However, there appears to be many gaps in provision and access to planning and services. There is a need for a mapping of existing services across Northern Ireland to identify key gaps in provision and to ensure equality of access to appropriate services.

Access to information

Articles 12 and 13 of the CRC give young people have the right to seek and receive information which will enable them to participate in decision-making and to make clarified choices about their futures on transition. Parents also have a right to receive support in raising their child (Article 18 CRC). The systems of planning for transitions are complex and the opportunities for young people after they leave school are diverse and may require negotiation.

Participation of young people in decision-making

Article 7(3) of the CRPD requires States Parties to ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Outside of the Children (NI) Order 1995, there is no statutory obligation on a public body to take young people's views into account in the decision-making processes around transition, although it is emphasised in guidance such as the Code of Practice on Special Educational Needs. Moreover, the extent to which it is happening in practice in a meaningful way is unknown.

Recommendations

Education, Training and Employment

There is a need for:

- Better and more consistent transitions planning and support.
- Statutory obligations to provide transition planning for all young people with learning disabilities and not just those with statements (or Co-ordinated Support Plans (CSPs)).
- A legal obligation to take young people's views into account in special educational provision generally and in transitions planning.
- A specific statutory obligation to make provision for young people in FE as well as a means of challenging decisions which are made about provision.
- Involvement of parents in the transitions process.
- Consistency across ELBs in age at which a young person has to leave MLD schools.
- Information and support for young people and their families about the transitions process and choices on leaving school.
- Greater communication and co-operation between education and health and social services.
- Appropriate and accessible post-school educational opportunities with real options for progression and lifelong learning opportunities.
- Opportunities for work experience while in school.
- Personal support for young people when they are settling into FE.
- A statutory obligation to support young people with learning disabilities on transition into FE and from FE to employment.
- Consistency across Northern Ireland in terms of transition support and supported employment opportunities.
- Targeted employment interventions.

Health and Social Care

There is a need for:

- Age appropriate and flexible day services and short break services.
- Need for continuity in social services provision when the young person attains the age of 18 but is still attending school.
- Opportunities to build up experience of attending day services while still at school.
- Good quality, resourced, educational and lifelong opportunities in day services.
- Greater co-operation in planning and decision-making across HSCTs.
- Greater transparency of information and support for parents about social care options available including on the range of accommodation, alternative sources of support and eligibility for services.
- Advocacy support for young people and their family carers.
- Equality of access to Transition Officers across the five HSCTs.
- Support for children and young people making transitions into and out of acute hospital care.
- Support and information on the transition to adult mental health services.
- Support to facilitate transitions to adult residential care and /or independent living.
- Age appropriate, tailored sexuality and relationships education.
- Information and advice for parents and carers on the types of family support available.
- Equal access for support for families across Northern Ireland.
- Support networks for parents and opportunities for young people to socialise.

Social Security, Leisure and Transport

There is a need for:

- Accessible information about entitlement to benefits.
- Support for the process of claiming benefits.
- Information and support to connect to the local community.
- Equal access to age-appropriate leisure opportunities.
- Support on the use of online tools.
- Individualised support to take part in age-appropriate leisure activities.
- Information and support for parents on supporting their son/daughter in accessing and participating in leisure opportunities.
- Opportunities for transport training and independent travel initiatives.
- Accessible information about public transport.
- Training on meeting the needs of young people with learning disabilities for staff in public transport and leisure services.

Chapter 1: Introduction

1.1 International Human Rights Framework

The United Nations Convention on the Rights of the Child (the 'CRC') was adopted by the General Assembly of the United Nations in 1989 and came into force in September 1990. It is the most widely ratified and comprehensive statement of children's rights standards covering most aspects of children's lives. The United Nations Convention on the Rights of Persons with Disabilities (the 'CRPD') was adopted by the General Assembly in December 2006 and came into force in May 2008. To date it has been ratified by 114 States, including the UK and, like the CRC, covers a wide range of civil, political, economic, social and cultural rights, in this case specific to the experiences of both children and adults with disabilities. Both the CRC and the CRPD are legally binding in international law. However, individuals cannot make complaints about breaches of their rights under either of these to a court. The primary enforcement mechanism for these treaties is through a system of periodic reporting to the Committee on the Rights of the Child, and the Committee on the Rights of Persons with Disabilities respectively with individual countries reporting on their progress in relation to their implementation every four (the CRPD) and five (the CRC) years. The most recent Concluding Observations issued by the Committee on the Rights of the Child in respect of the UK was in 2008. The UK is not expected to have its first examination by the Committee on the Rights of Persons with Disabilities until around 2014. The Committee on the Rights of the Child also issues General Comments (GC) which elaborate on the meaning of the various rights. Given that the work of the Committee on the Rights of Persons with Disabilities remains in the early stages, there have not yet been any General Comments in respect of the CRPD.

The Optional Protocol to the CRPD establishes a procedure allowing individuals and groups of individuals, including children, to raise complaints with the treaty body where they have exhausted domestic and regional remedies. It also establishes an inquiry procedure in relation to gross or systematic violations of the rights contained in the Convention. The UK has signed this Protocol. The Optional Protocol to the CRC on a communications procedure was opened for signature on 28 February 2012 in Geneva. The UK has not yet signed this Optional Protocol.

The focus of this project is on transitions to adult services for young people with learning disabilities with respect to education, employment and training, and health and social care.

Both the CRC and the CRPD have a number of articles which are directly relevant to this topic. While Article 2 and 23 of the CRC are the only ones which specifically mention 'disability', the Committee on the Rights of the Child has noted that the implementation of the Convention with regards to children with disabilities should not be limited to these articles (UN 2003, at para 5). The most relevant General Comments here are:

- General Comment 1 - The aims of education (2001);
- General Comment 4 - Adolescent health (2003);
- General Comment 9 - The rights of children with disabilities (2006);
- General Comment 12 - Right of the child to be heard (2009).

These observations will be drawn upon below. The transitions of young people with learning disabilities to adult services cannot be considered without looking at the CRC's general cross-cutting principles. These are as follows:

Article 2 – Non-discrimination

States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

Article 2 requires States parties to ensure that all children, including children with disabilities, enjoy all the rights enshrined in the Convention without discrimination of any kind. This obligation requires States parties to take a range of legislative, administrative and other appropriate measures to prevent such discrimination. The Committee has highlighted that discrimination in service provision excludes children with disabilities from education and denies them access to quality health and social services. Moreover, the lack of appropriate education and vocational training discriminates against them by denying them job opportunities in the future (UN 2006, at para 8).

Article 5 of the CRPD states that, in order to promote equality and eliminate discrimination, "States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided" (Article 5(3)). In addition, "specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention" (Article 5(4)).

Article 3 - Best interests of the child

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

The principle of best interests applies to all actions concerning children, including children with disabilities and requires “active measures to protect their rights and promote their survival, growth and well-being, as well as measures to support and assist parents who have day-to-day responsibility for realizing children’s rights” (UN 2005, at para 13). The Committee has stated that Article 3 should be the basis on which programmes and policies are set and it should be duly taken into account in every service provided for children with disabilities and any other action affecting them (UN 2006, at para 29).

Similarly, Article 7(2) of the CRPD states that: “In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.”

Article 6 - The right to life, survival and development

- 1. States Parties recognize that every child has the inherent right to life.*
- 2. States Parties shall ensure to the maximum extent possible the survival and development of the child.*

Article 6 gives the child a right to life, survival and development. ‘Development’ is here understood in its broadest sense as a “holistic concept, embracing the child’s physical, mental, spiritual, moral, psychological and social development” (UN 2003a, at para 12). As such, implementation measures should be aimed at achieving the optimal development for all children (UN 2003a, at para 12).

The Committee has observed that the right to survival and development can only be implemented through the enforcement of all the other provisions of the Convention, including rights to health, adequate nutrition, social security, an adequate standard of living, a healthy and safe environment, education and play as well as through respect for the responsibilities of parents and the provision of assistance and quality services (UN 2005, at para 10).

Article 12 - The right to express views and have these given due weight

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

The Committee has recognised that both children with disabilities and adolescents can face particular barriers in the realisation of this right (UN 2006, at para 32). The Committee has made it clear that children should be provided with whatever mode of communication they need to facilitate expressing their views. For instance: “children with disabilities should be equipped with, and enabled to use, any mode of communication necessary to facilitate the expression of their views.” (UN 2009, at para 115). Furthermore, States parties should support the training for families and professionals on promoting and respecting the evolving capacities of children to take increasing responsibilities for decision-making in their own lives (UN 2009, at para 32) as well as “continue and strengthen their efforts to take into consideration the views of children with disabilities and facilitate their participation in all matters affecting them within the evaluation, separation and placement process in out-of-home care, and during the transition process.”(UN 2006, at para 48).

Article 12 establishes that States parties shall assure the right to be heard to every child “*capable of forming his or her own views*”. However, the Committee makes clear that this phrase should not be seen as a limitation, but rather as an obligation for States parties to assess the capacity of the child to form an autonomous opinion to the greatest extent possible. This means that States parties cannot begin with the assumption that a child is incapable of expressing her or his own views. On the contrary, States parties should presume that a child has the capacity to form her or his own views and recognize that she or he has the right to express them; it is not up to the child to first prove her or his capacity (UN 2009, at para 20).

States parties must assure that the child is able to express her or his views “in all matters affecting” her or him. This means that the child must be heard if the matter under discussion affects the child. This basic condition has to be respected and understood broadly (UN 2009, at para 26). Finally, Article 12(2) specifies that opportunities to be heard have to be provided in particular “in any judicial and administrative proceedings affecting the child. Typical administrative proceedings include, “for example, decisions about children’s education, health, environment, living conditions, or protection.” (UN 2009, at para 32).

Article 7(3) of the CRPD requires States Parties to ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

The CRPD's General Principles

Article 3 of the CRPD explicitly sets out eight general principles. All provisions of the CRPD must therefore be read in light of these principles. They are as follows:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Substantive Rights

The focus of this project is on transitions to adult services for young people with learning disabilities. Both the CRC and the CRPD have a number of articles which are directly relevant to this topic.

While Article 2 and 23 of the CRC are the only ones which specifically mention 'disability', the Committee on the Rights of the Child has noted that the implementation of the Convention with regards to children with disabilities should not be limited to these articles (UN 2003a, at para 5).

The most relevant provisions are summarised below:

CRC	<p>Article 5 – the rights of parents to provide appropriate direction and guidance</p> <p>Article 17 – the right to information</p> <p>Article 18 – the rights of parents to appropriate assistance</p> <p>Article 19 – the right to protection from all forms of violence</p> <p>Article 20 – the rights of children deprived of their family environment</p> <p>Article 23 – the rights of children with disabilities</p> <p>Article 24 – the right to the highest attainable standard of health and health care</p> <p>Article 25 – the right to periodic review of placement</p> <p>Article 26 – the right to benefit from social security</p> <p>Article 27 – the right to an adequate standard of living</p> <p>Article 28 – the right to an effective education</p> <p>Article 29 – the aims of education</p> <p>Article 31 – the right to leisure, play and culture</p> <p>Article 32 – the right to be protected from economic exploitation</p> <p>Article 37 – the right not to be subjected to torture or other cruel, inhuman or degrading treatment or punishment</p>
CRPD	<p>Article 9 – the right to accessibility</p> <p>Article 15 – the right to freedom from torture or cruel, inhuman or degrading treatment</p> <p>Article 16 – the right to freedom of exploitation, violence and abuse</p> <p>Article 19 – the right to independent living and being included in the community</p> <p>Article 21 – the right to freedom of expression and opinion, and access to information</p> <p>Article 23 – respect for home and the family</p> <p>Article 24 – the right to education</p> <p>Article 25 – the right to the highest attainable standard of health and healthcare</p> <p>Article 26 – the right to habilitation and rehabilitation</p> <p>Article 27 – the right to work and employment</p> <p>Article 28 – the right to an adequate standard of living and social protection</p> <p>Article 30 – the right to participation in cultural life, recreation, leisure and sport</p>

1.2 Learning Disability

The Committee on the Rights of the Child has, in General Comment 9, adopted the definition of disability as contained within the CRPD. Specifically, that:

“Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (Article 1 CRPD).

The CRPD, in its preamble recognises that disability is an evolving concept and that disability results from “the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”. The Committee on the Rights of the Child has drawn on this also, stating that “the barrier is not the disability itself, but rather a combination of social, cultural, attitudinal and physical obstacles which children with disabilities encounter in their daily lives.” (UN 2006, at para 5).

The project team has adopted a rights-based definition of disability wherein:

*‘learning disability includes the presence of a significantly reduced ability to understand new or complex information or to learn new skills, with a reduced ability to cope independently, which started before adulthood with a lasting effect on development **and** which in interaction with various barriers may hinder full and effective participation in society on an equal basis with others.’¹*

There is no universally accepted definition of ‘learning disability’. Nor can people who have been formally diagnosed as having a ‘learning disability’ be understood as a homogenous group. Rather, they are a diverse group of individuals with similarly diverse needs, even among those who have been accorded the same diagnostic labels (Lewis and Porter 2004). Similarly, people with learning disabilities differ from each other in their circumstances and with respect to the range of barriers they may experience. A learning disability can be categorised as mild, moderate, severe or profound. In discussions which were conducted for this research, a recurring theme was the rise in the number of children and young people with very complex needs who are

¹ This definition combines the definition of learning disability adopted by the Bamford Review of Mental Health and Learning Disability (Equal Lives 2005) and Article 1 CRPD.

surviving into adulthood as a result of medical advances. In the UK, definitions of learning disability have traditionally been linked to IQ test scores (BILD 2004).

The 2005 Bamford Review 'Equal Lives' report highlights that international definitions of 'learning disability' includes three elements, all of which must be present: (1) significant impairment of intelligence that includes a reduced ability to understand new or complex information, and to learn new skills; (2) deficits in social functioning or adaptive behaviour and a reduced ability to cope independently; and (3) the disability started before adulthood and has a lasting effect on development. The level of communication and support needs can vary in severity not only between diagnostic groupings, but also within groupings. Some people with learning disabilities also have physical and/or sensory impairments, mental health difficulties, conditions such as Down's syndrome or cerebral palsy. Indeed Equal Lives (2005) indicates that mental health problems are much more frequent among people with a learning disability. Some people with learning disabilities may also have other conditions such as autism. Autism is a developmental disability rather than a learning disability in itself, and figures vary widely, but research suggests that around half of people with autism may also have a learning disability, which will affect the level of support they need in their life (Mencap 2012; Autism UK 2012).² People with a higher level autistic spectrum disorder who may be of average or above average intelligence such as those with Asperger's Syndrome are less likely to have a learning disability (Valuing People, 2001). The Autism Act (Northern Ireland, 2011) provides protection for people with Autism and amends the Disability Discrimination Act (1995) by including the following activities to the existing list: (i) taking part in normal social interaction, and (ii) forming social relationships. The Autism Act also requires an autism strategy to be prepared by the Department of Health, Social Services and Public Safety (DHSSPS) by 9 May 2013.

It is also important to distinguish between 'learning disability' and 'learning difficulty' – the latter is broader in scope and more likely to be educationally focused. For example, people with specific learning difficulties such as dyslexia are generally understood not to have 'learning disabilities' (Equal Lives 2005; Valuing People 2001; BILD 2004). There is a lack of comprehensive data available on the exact prevalence of learning disability. Emerson and Hatton (2008) estimate that in England, 210,510 (2.6%) pupils were identified as having a primary special educational need (SEN) associated with learning disabilities. There is no comparable data in Northern Ireland. However, the most recent

² <http://www.mencap.org.uk/all-about-learning-disability/about-learning-disability/learning-disability-and-other-conditions/cerebral-pals>: <http://www.autism.org.uk/about-autism/some-facts-and-statistics.aspx>

2011 Northern Ireland Annual School Census estimates that as a percentage of the total school population, the number of pupils with statements more generally had risen from 2.5% in 1996/7 to 4% in 2011 while the percentage of children at Stages 1-5 of the Code of Practice has increased from 14.6% in 2004 to 21% in 2011. 68% of the 12,973 of children with statements of SEN are currently placed in mainstream schools, or in units attached to mainstream schools, with the remainder attending special schools. In the context of learning disability specifically, it is estimated that, in Northern Ireland, the prevalence of learning disability in the 0-19 age range is 16.30 per 1000 (McConkey et al 2003).

The 2005 Bamford report 'Equal Lives' estimates that 180 young people with severe and profound learning disabilities leave school each year. In addition, significant variation exists across further education colleges in the number of students with a learning disability enrolled as a proportion of the student body ranging from 1%-13% in 2002 (Department for Employment and Learning 2002).

1.3 Transitions

A 'transition' implies a shift from one period or phase to another. 'Transition' is a term often used to refer to the time in a young person's life when plans are made to move from school to adult life and services. Young people with learning disabilities can often experience complex and 'extended transitions' (Caton and Kagan 2007) due to the range of barriers they may face across education, health and social services, and employment (Coles 1997; Cameron and Murphy 2002; Hudson 2003, 2006; Beattie 1999; Pilnick et al 2011). Compared with non-disabled young people, the experiences of those with learning disabilities are more likely to be characterised by wider scope, longer duration and attenuated experiences (Hudson 2003).

Successful transition planning is contingent on a number of factors. Core to this process are the 'five Cs', that is: communication, coordination, comprehensiveness, continuity and choice (Heslop et al 2002).

Specifically, research suggests that successful transition requires:³

³ Beresford 2004; Kaehne and Beyer 2009; Carnaby et al 2003; Lynggaard 2002; Gillan and Coughlan 2010; Heslop and Abbot 2007; Hudson 2003; Ward et al 2003; Tarleton and Ward 2005; O'Connor et al 2005; Smyth and McConkey 2003.

1. Person-centred, forward planning;
2. Meaningful participation of young people and their parents throughout the transitions process;
3. Provision of support for young people and their parents during the process;
4. A multi-agency approach;
5. Availability of a range of services and options covering all major areas of adult life (e.g. continuing education, employment, residence, daily living, health, leisure, communication, inter-personal skills, self-determination and community participation);
6. Accessible information about options;
7. Providing a firsthand look at the range of options available;
8. Person-centred, flexible provision;
9. Follow-through.

In Northern Ireland, a key transition for young people with learning disabilities will be the transition from post-primary school. For some (those attending mainstream schools and MLD schools which do not have post-16 provision) this will occur at 16 and for others (those attending SLD schools and those attending MLD schools with post-16 provision such as a leavers programme) it will be at 18/19. Young people with significant health and social care needs will also experience a transition from child to adult services. Transition to social services usually takes place at 18, although the age at which young people are no longer eligible for a service may vary from service to service. The age for transition within health services also varies. Access to school nurses and allied health services may continue while the child is at school but transitions to hospital care or other health services such as paediatric services can happen much earlier, normally at 14.

1.4 The Northern Ireland Policy Context

Transitions to adult services have long been identified as a significant issue in need of reform in Northern Ireland. There are a number references to the complexity of transitions throughout policy documents, departmental reports, research and local initiatives; both in the context of disability and/or special educational needs generally, and in the context of learning disability specifically. The extent to which the identified issues have been effectively addressed in practice is, however, less evident and the primary focus has been on the transition planning process itself rather than transition outcomes.

An overview of the policy context is set out below:

In 2002, an Inter-Departmental Group (IDG) formed by the Departments of Education, Employment and Learning, and Health, Social Services and Public Safety were asked to consider how the transitions process could be improved for young people with statements of special educational needs. The group published their report in 2006. Significantly, this contains an action plan, which provides over 20 actions to address some of the many issues that were presented to the group. The IDG report reflects the findings of two surveys conducted by the Education and Training Inspectorate (ETI) highlighting the strengths and weaknesses of the transition planning process for school leavers in special schools (ETI 2004a) and students with learning difficulties and/or disabilities (SLDD) in Colleges of Further Education (ETI 2004b). This was followed in 2008 by a third ETI report on an overview of existing school-based transition arrangements and an evaluation of the work of Transition Co-ordinators.

The Promoting Social Inclusion (PSI) Working Group on Disability made a number of recommendations on transitions to adulthood for young people with disabilities in its 2009 report. It set out as one of its goals, that “every disabled young person should lead a confident, enriched life and be given the appropriate supports to make a seamless transition to a fulfilled adult life in which they can participate socially, politically, culturally and economically” (p.9). A Disability Strategy, based on the recommendations of the PSI Working Group is currently out for consultation by the Office of the First Minister and deputy First Minister (OFMDFM). The purpose of the strategy is to set out a high level policy framework to give coherence and guidance to government departments’ activities across general and disability specific areas of policy. Among the 16 strategic priorities proposed by the strategy is Strategic Priority 10 ‘Transitions to Adulthood’ which seeks to ‘transform the process of transition to adulthood for young people with disabilities’.

The consultation document on the Review of Special Educational Needs and Inclusion (2009) has a specific section on transition points to adulthood. This reiterates many of the IDG recommendations and proposes a more effective and consistent transitions process and a more equitable transitions support service. The consultation process on the proposals was completed in January 2010, and an update on the Review was provided in January 2012 along with a further update in May 2012.

At the time of writing the proposals are still subject to development. However, it is anticipated that a policy memorandum will be submitted to the Executive by summer 2012.

The issue of transitions with respect to young people with learning disabilities specifically has been highlighted by the Bamford Review of Mental Health and Learning Disability, a wide-ranging, independent review of the law, policy and service provision affecting people with a mental health problem or a learning disability. Of the 10 reports between June 2005 and August 2007, the Equal Lives report (2005) makes a number of recommendations specific to transition planning (recommendations 14-16), employment (18-20) as well as recommendations on associated issues such as travel training, leisure and personal relationships (21-26). Some of these recommendations have been taken forward by the Northern Ireland Executive in 'Delivering the Bamford Action Plan' 2009-2011. A new action plan is currently being developed. With respect to health and social care, the Compton Review 'Transforming Your Care' (2011) sets out proposals relating to, inter alia, the development of age appropriate day and short break services, the provision of information on services, and promoting the uptake of Direct Payments among people with learning disabilities.

More broadly, the Ministerial Sub Committee on Children and Young People (2007-2011) identified transitions to adulthood as a key priority in their work. The Northern Ireland Executive's contribution to the UK's periodic report on the CRPD notes that an Action Plan has been developed by a sub group of the Ministerial Sub Committee on Children and Young People, chaired by the Department of Education. The report notes that the sub group has focused on the area of transitions for children and young people with special educational needs from school or college to employment, training or social care settings and that "a range of actions is expected to be delivered in 2011/12". However, the document does not specify what these particular actions are and it has not been possible to track down further information on the work of this group. At the time of writing the work of the Ministerial Sub Committee is under review as part of the wider OFMDFM Delivering Social Change framework.

The Children and Young People's Strategic Partnership (CYPSP), which was established in January 2011, has established five Outcomes Groups and currently has six Regional Sub Groups to plan for specific groups of children and young people and to address key issues. The CYPSP is a cross sectoral, strategic partnership, consisting of the leadership of many key agencies who deliver services for and have responsibility for improving outcomes for all children and young people in Northern Ireland, including community and voluntary sector organisations. Among the Sub Groups that have been established are the Children and Young People with Disabilities Sub Group and the Transitions Sub Group. The Transitions Sub Group is currently developing an action plan that will set out what it will do to ensure that outcomes for young disabled people at

transition to adulthood are improved. The Sub Group will decide on a set of indicators which will be used to measure how well young disabled people at transition to adulthood are doing in Northern Ireland over time. In addition, each of the CYPSP five Outcomes Groups have produced draft consultation documents on their proposals. The consultation process ended on 11 April 2012. Key themes include 'supporting vulnerable children and young people and their families during key transitional stages of the educational continuum' and early intervention (Belfast Outcomes Group); Access to family support services for children with disability across all locality areas, and early intervention (Northern Outcomes Group); improved family support and data collection on disability (South Eastern Outcomes Group); and family support, early intervention and 'working together to enhance the achievement of all children and young people throughout their time in, education, training, and into employment' (Southern Outcomes Group).

A consultation process on a draft Learning Disability Service Framework ended on 12 March 2012. The aim of the Learning Disability Service Framework is to improve the health and wellbeing of people with a learning disability, their carers and their families by promoting social inclusion, reducing inequalities in health and social wellbeing, and improving the quality of care (2012-2015). In addition to standards specific to children with learning disabilities with respect to education, health, and support and assessment, standard 12 states that 'Young people with a learning disability should have a transition plan in place before their 15th birthday and arrangements made for their transition to adulthood by their 18th birthday'. Also currently being developed is the Children and Young People's Health and Wellbeing Service Framework. The overall aim of this Framework is to improve the health and wellbeing of children and young people in Northern Ireland, promote social inclusion, reduce inequalities in health and improve HSC quality of care and thereby improving population health outcomes across the life course. Both these Service Frameworks and the CYPSP are being led by DHSSPS and the Health and Social Care Board (HSCB).

Chapter 2: Education, Employment and Training

2.1 Transitions Planning in Education

2.1.1 International Standards

The Committee on the Rights of the Child has said that: “Education must also be aimed at ensuring that ... no child leaves school without being equipped to face the challenges that he or she can expect to be confronted with in life. Basic skills should include ... the ability to make well-balanced decisions; to resolve conflicts in a non-violent manner; and to develop a healthy lifestyle [and] good social relationships ... and other abilities which give children the tools needed to pursue their options in life.” (UN 2001, at para 9). Effective access of children and young people with disabilities to education has to be ensured in order to promote “the development of the child’s personality, talents and mental and physical abilities to their fullest potential.” (UN 2006, at para 62). Education also has to provide the child with “empowering experience of control, achievement, and success to the maximum extent possible for the child”. (UN 2006, at para 64). The Committee on the Rights of the Child has also emphasised the importance of education for career development and transition for people with disabilities (UN 2006, at para 68) but it has not elaborated specifically on the latter.

Article 24(3) of the CRPD requires States Parties to enable people with disabilities to “learn life and social development skills to facilitate their full and equal participation in education and as members of the community” while Article 24(5) requires States Parties to “ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others”.

2.1.2 Law, Policy and Practice

The current statutory requirements in relation to educational transitions for children with learning disabilities depend largely on whether the child has a statement of special educational need. If a child is statemented, the first review of the child’s statement after their 14th birthday requires the Education and Library Board (ELB) to prepare a transition plan (Special Educational Needs Regulations (NI) 2005). Before it does so, it must seek advice from the child’s parent and any other person the ELB or principal considers appropriate. The ELB must also seek an opinion from the HSCT as to

whether the child is a disabled person and may require services from a HSCT when leaving school (Disabled Persons Act 1989 s. 5). The Code of Practice on SEN gives guidance on the issues to be considered at the first annual review after the 14th birthday. Reviews subsequent to this do not have specific regulations but the Code suggests that the subsequent annual reviews should consider whether the Transition Plan is helping the pupil's progress to adult life. If a child does not have a statement of special educational need, there is no specific obligation to have a transitions meeting. The Code of Practice states that ELBs and schools should seek to provide appropriate help and guidance and may wish to prepare their own transition plans for these students. There is no legal obligation to do so. There is also no legal obligation to consult the young person in the transition processes, whether they are statemented or not. However, the supplement to the Code of Practice states that their views should be sought and recorded (6.49-6.50). Moreover, as part of the SEN review, the Department of Education (DE) has said it will consider how existing legislative provision could be amended to require the views of the child to be sought.⁴ One of the parents we spoke to described how valuable it had been when a Mencap Transitions Officer worked with her son, enabling him to express his views about what he wanted on transition. She said that it had helped her to see it from his point of view and to change her ideas about what would be most useful for him.

The Transitions Inter-Departmental Working Group report (2006) recommended the appointments of Transitions Co-ordinators to strengthen the transition planning process in school and provide a co-ordinated approach with other statutory agencies and advice givers. As a result of this, DE made additional funding available which enabled the ELBs to appoint Education Transition Co-ordinators to strengthen the transition planning process in school, to support the young person and their parents in preparation for leaving school, to provide a co-ordinated approach with other statutory agencies and advice givers and to provide life skills training in schools. The 2009-2011 Bamford Action Plan specifies the need to mainstream the funding of the 5 Education and Library Board Transition Services. The young people we spoke to and their parents valued the work of the Transition Officers as well as additional support provided by voluntary organisations such as Mencap. However, practice appears to vary and, for instance, Transition Officers are not always able to attend all annual reviews.

⁴ Department of Education (May 2012) 'Review of SEN and Inclusion: Minister's Presentation to the Committee for Education - Wednesday 16th May 2012 (Policy Development)', <http://www.niassembly.gov.uk/Assembly-Business/Official-Report/Committee-Minutes-of-Evidence/May-2012/Review-of-Special-Educational-Needs-Ministerial-Briefing/>

When a child is statemented, the school will invite a range of professionals to contribute to the planning process including the Education Transition Officer, the Health and Social Care Transition Officer, any allied health professionals and psychologists where necessary. Concerns about this process from a schools' perspective include:

- The difficulty working across different ELBs and HSCTs since not all of the latter have Transition Officers.⁵
- Delays in getting agreements about where the young person with severe learning disabilities will be going when they leave school.
- Difficulty in finding out and navigating what is available for students when they leave school and a lack of control or input into what will happen.

The 2004 ETI report also highlights the transition arrangements for students attending SLD and MLD schools. It states that there is a leavers' programme in all SLD schools for 16-19 year old pupils. However, in SLD schools, concern was expressed at the lack of adult service placements, compounded by waiting lists and at inappropriate placements relating to an unsuitably wide age-mix. In MLD schools, it was found that transition arrangements were 'well established and detailed' with early identification of post-school placements. However, one of the key findings in the survey relates to the issue of transfer at age 16 for a minority of pupils who clearly would benefit from a further year in the MLD school. Practice is not consistent across the ELBs and continues to be a source of some confusion and concern. Finally, a significant issue arose in regard to the placements identified for the young people who may fall into the borderline 'severe' learning disability category and for whom the solution was to be transferred to SLD schools at age 16 (ETI 2004a, p.20), most notably in the South Eastern Education and Library Board.⁶ That said, for one young person and his family whom we spoke to, an earlier transition from an MLD to SLD level school has been a huge success: the young person had struggled with the more academic orientation of the MLD school and was enjoying and benefitting from the more practical focus in the SLD school he attended. In another case, the mother of a young person who attended a mainstream school negotiated with the school to ensure her son was offered a bespoke package which enabled him to stay on at school. While some of his peers

⁵ All ELBs have Transition Officers. Due to lack of information across HSCTs it is not possible to confirm actual numbers. However, it would appear that at least two HSCTs do not have dedicated Transition Officers/Workers.

⁶ A list of learning disability schools in Northern Ireland by type, ELB and leaving age is provided in the appendix.

were heading to FE, neither he nor his mother felt he was ready for that and should be able to stay on at the school which offered post-16 provision to those wishing to do A-levels.

The ETI survey identified the need for a Strategic Forum for Transition, involving health and education providers. It was envisaged that such a grouping should be given the responsibility and resources to produce a Transition service level agreement to provide effective guidance to schools and adult providers. The issue is currently being discussed by the Transitions Sub Group of the Children and Young Person's Strategic Partnership Board. The Audit of Inequalities carried out by the Staff Commission for Education and Library Boards in 2011 recommended that a review be undertaken of the implementation of the ETI's recommendations on its 2008 evaluation of the transition arrangements from special school to 'Further Education, Adult and Working Life' and which, *inter alia*, called for greater collaboration between the education, health and careers services.

Much of the existing statutory provision for transition is dependent on the child having a statement of special educational need. However, under the proposed reforms of special education, the Department has indicated that statements of need will be set out in the form of Co-ordinated Support Plans (CSPs) and that there will be fewer of these.⁷ The latest proposals indicate that CSPs would be awarded to "*some children in mainstream classrooms, all children in learning support centres attached to mainstream schools and all children in special schools*".⁸ The Minister has suggested that the existing legislation will not be replaced but will be amended: this would mean that the existing provision for transition planning will be retained but will be a statutory requirement for fewer young people than is currently the case. Young people with learning disabilities who do not have CSPs will have Personal Learning Plans (PLPs). It is proposed that there will be a legal obligation on schools to ensure that children who need them have a PLP. However, there is little concrete detail on these at present, and proposals have yet to be

⁷ Department of Education (January 2012) 'Summary Report of Responses to the Consultation on Every School a Good School – The Way Forward for Special Educational Needs and Inclusion and the associated Equality Impact Assessment' (Bangor: DE); Committee for Education, Special Educational Needs and Inclusion, Official Report (Hansard) Session 2011/12 Northern Ireland Assembly, Hansard 18 January 2012. <http://www.niassembly.gov.uk/Assembly-Business/Official-Report/Committee-Minutes-of-Evidence/January-2012/Committee-for-Education---Special-Educational-Needs/>

⁸ Department of Education (May 2012) 'Review of SEN and Inclusion: Minister's Presentation to the Committee for Education - Wednesday 16th May 2012 (Policy Development)', page 34 <http://www.niassembly.gov.uk/Assembly-Business/Official-Report/Committee-Minutes-of-Evidence/May-2012/Review-of-Special-Educational-Needs-Ministerial-Briefing/>

finalised. The original 2009 consultation proposals suggested that all pupils with SEN, in addition to those with statements, should have access to the Transitions Support Services. However, as of 16 May 2012, the Department has withdrawn the proposal to extend the current statutory arrangements for annual transitions reviews for pupils with statements (from 14 until leaving school) to all pupils with SEN, reasoning that *“the original proposal could result in an increased bureaucratic burden on schools with limited, if any, additional benefit to the pupils.”*⁹ Moreover, it is proposed that full annual reviews will no longer take place automatically but, instead, that a parent or school will have a right to call for annual review.¹⁰ It is important to note that at the time of writing the SEN and Inclusion policy proposals remain subject to development, however, the Minister for Education has indicated an intention to submit a policy memorandum to the Executive in the near future.¹¹

2.1.3 Summary of Issues of Concern

- Availability and adequacy of transition planning, support and real options to move into, varying across ELBs and HSCTs.
- Reduced level of provision and statutory protection for children who will no longer be defined as having a statement of special educational needs under the current proposals.
- Full annual reviews no longer mandatory under the current proposals.
- Variation across ELBs in age at which a young person has to leave MLD schools.
- Lack of specific legal obligation to take young person’s views into account.
- The need for greater communication and co-operation between education and health and social care.
- Lack of information and support for young people concerned and their families about the process and choices available on leaving school.
- Delays in HSCT decision making processes about the services and support that will be available which impacts on and limits the ability of schools, parents and young people to plan and prepare for the future.
- Inadequacy of interagency/joint working between sectors (including the voluntary sector) and staff involved in transitions work across Northern Ireland.

⁹ *Supra* note 8 at p.45.

¹⁰ *Supra* note 8.

¹¹ NI Assembly Committee for Education (16 May 2012) Official Report (Hansard) ‘Review of Special Educational Needs: Ministerial Briefing’ 16 May 2012.

2.2 Access to Effective Education and Training on Leaving School

2.2.1 International Standards

Article 28 of the CRC obliges States parties to:

- Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child;
- Make educational and vocational information and guidance available and accessible.

Young people with learning disabilities have the same right to education as all other young people. There is no right within the CRC for compulsory secondary and post-secondary education. However, in General Comment 4, the Committee on the Rights of the Child has stressed that in accordance with article 23(3) of the Convention, the rights of *adolescents with disabilities* should be taken into account and assistance provided to ensure that the disabled child/adolescent has effective access to and receives good quality education on the basis of equal opportunity and without discrimination (UN 2003b, at para 19). Article 24 of the CRPD obliges States Parties to ensure “an inclusive education system at all levels and lifelong learning...”.

Such education and lifelong learning should be directed at:

- (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- (c) Enabling persons with disabilities to participate effectively in a free society.

2.2.2. Law, Policy and Practice

If a young person is educated in an SLD school or MLD school which has post-16 provision, the statutory statement of special educational needs will normally continue until he or she leaves school at 18 or 19. If a young person attends a mainstream

school or an MLD school which finished at 16, then the statement will cease when he or she leaves school which will normally be at 16. Some parents may choose to seek admission to a special school at this point to maintain the level of support and provision in the statement. If a child at a mainstream school does not have a statement then there is no specific obligation on an ELB to maintain or review educational support and provision.

Once a young person leaves school, formal education will normally be provided in FE colleges. Transition Officers in ELBs often liaise with FE colleges. The Further Education (Northern Ireland) Order 1997 requires governing bodies of institutions of further education, in the discharge of their duties under Article 13(1), to have regard to the needs of students over compulsory school age who have learning difficulties. The disability discrimination provisions of the Special Educational Needs and Disability Order (SENDO) apply to FE provision and there is a specific Code of Practice on Disability Discrimination in FE and Higher Education (HE). In relation to transition, the obligations in relation to the admissions of students are most relevant. A college can only justify its refusal to allow a student with a learning disability onto a course after every reasonable adjustment is investigated and it can be clearly demonstrated that the student cannot meet the academic or prescribed standards. FE colleges are funded by the Department for Employment and Learning (DEL) to provide for students with learning difficulties and/or disability (SLDD). They receive recurrent funding as part of their main budget and Additional Support Funding (ASF) which can be used for mainstream provision or discrete provision for students with SLDD. Colleges have to complete a Supplementary Learning Agreement for all students for whom ASF is claimed (Circular FE 08/11). This includes a requirement to identify the reasonable expectations of the outcomes of course participation and the identification of progression routes.

In terms of educational opportunities available to young people after leaving school, FE college provision also differs from campus to campus. Concerns were expressed in the Equal Lives report at the lack of available options after school and the lack of progression from FE provision: students not able to gain accredited awards from their study; the lack of links with job training and work experience; and students repeating the same course content in subsequent years (2005 p.47). A second report by ETI in 2004 focused on the provision made for students with learning disabilities within mainstream college courses and in discrete courses across five colleges. This indicated that while there have been positive developments in the provision made for students with learning disabilities, there was a need for colleges to: review their learning support structures to

ensure provision exists across the curriculum areas for students with learning disabilities; and to ensure broader access to appropriate nationally accredited courses.

With respect to further education, research suggests that young people with moderate learning disabilities can spend prolonged time on courses; referred to as the so-called 'merry-go-round', where students can enrol on course after course, year after year without any real progression (Caton and Kagan 2007; Kaehne and Beyer 2011. See also Equal Lives (2005) with respect to people with learning disabilities more generally). This was a concern expressed by the young people who have been consulted by the Transition Sub Group of the CYPSP group. In a recent report by the Bamford Monitoring Group, young people with learning disabilities across five further education colleges indicated that they would like more choice at colleges including being able to choose course options themselves. The report recommended that young people are actively involved in decisions about courses; that colleges prepare students for work and life after college; and that DHSSPS and DEL should collaborate to ensure that further education for people with learning disabilities is protected and enhanced in line with service user needs (Bamford Monitoring Group 2011). Parents and young people we spoke to also considered the lack of choice at FE to be an issue. One parent reported that her daughter wanted to do a course on hairdressing or beauty but that was not an option within the Steps to Work programme at the local college. She expressed her concern in terms of a lack of equality for young people with learning disabilities in relation to the opportunities available to them and their ability to follow their own interests.

There is also significant concern about the educational opportunities available to young people with more severe and profound learning disabilities when they leave school. Most of these young people attend day care centres. Although these services will offer a range of activities, they do not have an education focus and young people will not have an individual education plan or assessment. Parents expressed concern that many of these young people are on a developmental trajectory which takes longer than other children, but which can come abruptly to a halt when the young people leave school at 18 or 19 and thus impacts on their general right to an effective education.

2.2.3 Summary of Key Issues of Concern

- Availability and accessibility of suitable post-school educational opportunities.
- Need for genuine options, progression and lifelong learning opportunities in terms of education and training.

- Personal support for young people when they are settling into FE.
- Policy, government targets and interventions more generally do not always reflect the needs of young people with learning disabilities.

2.3 Employment

2.3.1. International Standards

The right to work and employment without discrimination is contained in Article 25 of the CRPD. This includes the right to a work environment that is open, inclusive and accessible. States Parties are also required to: enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training (25d); promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment (25e); ensure that reasonable accommodation is provided to persons with disabilities in the workplace (25i) and; promote the acquisition by persons with disabilities of work experience in the open labour market (25j). Article 32 of the CRC recognises the right of the child to be protected from economic exploitation and from performing any work that is likely to be harmful to the child's health or physical, mental, spiritual, moral or social development.

2.3.2 Law, Policy and Practice

The key obligations in relation to the transition of people with disabilities begin while they are at school and, as reported above requires transition planning which should include careers advice. DEL, although facing dissolution, is currently the key public body with statutory responsibility in this area. It is required, like all public bodies, to promote positive attitudes towards disabled people and to encourage participation in public life, (Article 49A as amended by Article 5 of the Disability Discrimination (DD) (NI) Order 2006) and to promote equality of opportunity (Section 75 NI Act 1998). In practice, DEL fulfills its functions through the Disability Employment Service (DES) which funds a range of services including: Job Introduction Scheme: Workable (NI); Access to Work NI; and Employment Assessment and Occupational Psychology Services; and the Ulster Supported Employment (USEL), a non-departmental Public Body. DEL is also required by law to submit a Disability Action Plan and Section 75 Equality Scheme explaining how they propose to fulfill their duties. The most recent Disability Action Plan (2009/11) does not mention work or plans to support young

people making transitions from school specifically. Finally, employers are bound by the obligations in the Disability Discrimination Act and are therefore required not to discriminate and to make reasonable adjustments. DEL has published some literature showing case studies of young persons with learning disabilities in employment, highlighting examples of positive practice.¹²

Research indicates that, while many people with learning disabilities aspire to having a job, opportunities for achieving fulfilling paid employment are scarce (McLaughlin, Monteith and Sneddon (2000). Beyer (2008), for example, has highlighted that, transition planning for young people with a learning disability is more likely to lead to a five-day college placement or day service place rather than an employment option. Research indicates that successful transition with respect to employment requires:¹³

1. Involvement of external employment agencies in transition planning;
2. Availability and provision of 'real' work-experience placements with feedback;
3. Solid exit route into paid employment;
4. Availability of supported employment options;
5. Accessible information on employment and benefits;
6. Supportive vocational curriculum;
7. Supporting mainstream employers to adapt working practices and workplace 'culture';
8. Support mechanisms for young people with learning disabilities in the workplace;
9. Inclusive and empowering service approaches.

In order for young people with learning disabilities to make the transition to paid employment, they need to get careers planning and appropriate work placements while they are still at school and/or in FE. The 2008 ETI report states that in MLD schools, pupils have annual work experience placements extending from one to two weeks as they progress through Key Stage 4. In SLD schools, the pupils for whom work experience has been identified as suitable participate in a range of in-house and community-based placements as they progress through post-16 provision. One young person we spoke to had benefited enormously from his part-time work experience and he and his family valued the support he had received to do this from a voluntary

¹² <http://www.delni.gov.uk/workable-pink-may08.pdf> Accessed 04 April 2012.

¹³ Beyer 2008; McLaughlin, Monteith and Sneddon 2000; Gillan and Coughlan 2010; Kaehne and Beyer 2009; Beyer and Kaehne 2010; McConkey and Mezza 2001; Taylor et al 2003; Gosling and Cotterill 2000; Kambouri and Corbett 2000.

organisation. However, while there is a variety of valuable external transition support programmes available, largely through NGOs, to schools and FE colleges throughout Northern Ireland, uptake of these appears to vary from school to school, college to college and area to area. Placements had been organised through family members for many of the young people to whom we spoke.

There is also concern at the lack of any statutory transition support at the end of further education to assist people to enter employment, meaning that young people tend to remain in further education settings for overly long periods of time and/or fall back into daycare services rather than pursuing employment options (Kaehne and Beyer 2009). The PSI report (2009) highlighted the lack of a consistent and comprehensive approach towards the planning, delivery, monitoring and evaluation of transition from education and employment, including the lack of support for people with a disability who fall outside the statementing criteria. It recommended that young people with disabilities have access to a full range of training opportunities so that they can make the transition to employment, and emphasised the development of a strategic plan which clearly sets out a comprehensive, person-centred transitions process with a focus on early intervention and employability, and the social skills necessary for life beyond school.

Although evaluations of government-based employment schemes for people with disabilities highlight the benefits of such programmes to individual participants, a significant proportion of the trainees do not make the transition to paid work (Equal Lives 2005, Monteith 2000). For example, an evaluation of the Workable (NI) programme indicated that this was less successful than the Workstep programme in GB in terms of the progression of participants into open employment: 9% progressed to unsupported employment in Northern Ireland compared to 14% in GB (KPMG 2010). The report also highlighted that the majority of people on the programme had a learning disability. Equal Lives (2005) found that access to mainstream employment programmes can be limited by factors such as: admission criteria, the outcomes required, duration of the programme and the pattern of provision. Other factors include: the absence of clear intra-agency partnerships, low expectations and inflexible benefits rules. For instance, Workable (NI) only applies to employment of over 16 hours a week which is not suitable for all and also has knock-on effects on benefit entitlements for those who participate. Access to supported employment also varies considerably on a regional basis in spite of the considerable growth in Supported Employment in Northern Ireland over the last twenty years. However, funding for Supported Employment is heavily dependent upon the European Social Fund (ESF) funding and is not mainstreamed.

More generally, people with learning disabilities have raised concerns that they are expected to work for nothing or considerably less than others (Patient Client Council (PCC) 2012). A related concern is that employers, particularly in a recession, will not always be able to offer sixteen hours of work, thus limiting opportunities in organizations which are committed to the employment of people with learning disabilities.

2.3.3 Summary of Issues of Concern

- Lack of specific statutory obligations to support young people with learning disabilities on transition into FE and from FE to employment.
- Need for more opportunities to get work experience while in school.
- Variation in access across Northern Ireland both in terms of transition support and supported employment opportunities.
- Restriction of Workable (NI) to those engaging in at least sixteen hours of work a week.
- Impact on social security benefits of part-time working.
- A need for targeted interventions which recognise the adjustments and extra support that is needed.

Chapter 3: Health and Social Care

3.1 Social Care

3.1.1. International Standards

The Committee on the Rights of the Child has referred specifically to adolescents with a mental health ‘disorder’. Whilst clearly distinct from learning disability, the commentary here provides useful guidance with respect to the experiences of young people with learning disabilities who live outside the family home. Specifically, the Committee has said that: “Every adolescent with a mental disorder has the right to be treated and cared for, as far as possible, in the community in which he or she lives.” Moreover, in the event of hospitalization or institutionalization, the young person should be given “the maximum possible opportunity to enjoy all his or her rights, including the rights to education and to have access to recreational activities.” The Committee has also stipulated that “Where appropriate, adolescents should be separated from adults” and that States parties “must ensure that adolescents have access to a personal representative other than a family member to represent their interests, when necessary and appropriate.” In accordance with article 25 of the CRC, States parties should also undertake periodic review of the placement of adolescents in hospitals or psychiatric institutions (UN 2003b, at para 2). In addition, Article 20 of the CRC gives children who are temporarily or permanently unable to live with their families, the right to special protection and assistance by the State. As such, Article 20(2) requires States parties to ensure alternative care for these children.

The Committee has further emphasised that institutions providing care for children with disabilities are staffed with specially trained personnel, subject to appropriate standards, regularly monitored and evaluated, and have accessible and child-sensitive complaint mechanisms (GC 9, at para 44-48).

Article 19 of the CRPD recognises the equal right of all persons with disabilities to live in the community, with choices equal to others. States Parties are required to take effective and appropriate measures to ensure that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 26 of the CRPD requires States Parties to take measures to enable people with disabilities to “attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”. As such, States Parties are required to “organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
- (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.”

3.1.2 Law, Policy and Practice

The legislation on the provision of social care for young people with disabilities is disparate and complex. When the young person is under 18, they will fall within the definition of a child under the Children (NI) Order 1995. Moreover, a young person with a learning disability is considered a ‘child in need’ due to their disability under the Order. The Order makes provision for HSCTs to promote and safeguard the welfare of children who are in need, including by providing health and social services assessments.¹⁴ It also gives specified authorities (including HSCTs, ELBs and NI Housing Executive) the power to request assistance from other authorities. These requests should be complied with if it is compatible with that bodies’ own statutory duties and obligations.¹⁵ There is also a specific obligation to make an assessment of the needs of young people with

¹⁴ Article 18.

¹⁵ Article 46.

statements when they are 14 and at the time of a reassessment after that birthday.¹⁶

Once in adult services there is a general obligation on HSCTs to assess the needs of the person with disabilities,¹⁷ taking into account the abilities of the carers.¹⁸ The Order also contains provisions relating to the provision of alternative accommodation by specified authorities where it is so required by a 'child in need',¹⁹ and/or where there are safeguarding concerns (up to the age of 16, and between 16 and 21 in certain circumstances).²⁰ HSCTs have an obligation to determine whether the child's welfare is adequately safeguarded and promoted while they are accommodated by the HSCT whether in residential care or in a hospital setting.²¹ The Children (Leaving Care) Act (NI) 2002 amends the Children Order. It places duties on the five HSCTs to assess and meet the needs of young people until they are at least 21 years old. The Act does this by, for example, placing a duty on HSCTs to keep in touch with young people who have left care and to ensure they get the support to which they are entitled. These duties extend until the young person's 21st birthday or beyond this if they are in higher education/training. The Carers and Direct Payments Act (Northern Ireland 2002) gives carers the right to request an assessment of their individual needs and places an obligation on HSCTs to meet the needs of carers as assessed. The Act contains a duty to provide the services required, yet no extra funding was earmarked to meet the requirements of the Act.²²

When it is considered necessary to meet the needs of the person, HSCTs must make arrangements for all or any of the following: practical assistance for that person in his/her home; games, outings or other recreational facilities outside his home or assistance to that person in taking advantage of educational facilities available to him; facilities for, or assistance in, travelling to and from his home for the purpose of participating in, any services; carrying out of any works of adaptation in his home or the provision of any additional facilities designed to secure his greater safety, comfort or convenience; facilitating the taking of holidays; assistance in obtaining a telephone and any special equipment necessary to enable him to use a telephone.²³ Many of the existing services are provided by HSCTs although a number are funded and provided

¹⁶ Disabled Persons (NI) Act 1989, s. 5.

¹⁷ Article 3 of the Disabled Persons Act (NI) 1989.

¹⁸ Ibid Article 8.

¹⁹ Article 21 Under the Children Order (NI) 1995 children with disabilities are defined as children 'in need'.

²⁰ Article 21.

²¹ Article 174.

²² <http://www.lawcentreni.org/policy/policy-briefings/210.html>

²³ Chronically Sick and Disabled Persons (NI) Act 1978.

for by voluntary organisations such as Mencap, the Cedar Foundation and the Now project. While these are highly valued by parents and young people, concern was expressed about the limited resources available, the ad hoc nature and sustainability of the funding and the lack of consistency in provision across Northern Ireland.

Provision can be made through direct payments to the young person or their carer, enabling them the independence to purchase the services they want. Research suggests that there is a low uptake of direct payments by people with learning disabilities in Northern Ireland. In 2007, of the 922 people receiving direct payments, 92 were people with learning disabilities under the age of 21 (10%) while 109 were aged 21 and over (12%) (Glasby and Littlechild 2009; see also Equal Lives 2005; PSI 2009). Identified barriers to take up include an assumption that direct payments are not appropriate for people with learning disabilities due to a perceived lack of capacity to use and manage such payments; a lack of awareness about direct payments; and a lack of information in accessible formats about how to access them and what they can be used for (Glasby and Littlechild 2009; Priestley, Jolly et al 2007) Indeed, Priestley, Jolly et al (2007), exploring direct payments across the UK including Northern Ireland have highlighted concern about the extent to which independent living outcomes for disabled people may depend on local discretion in assessing entitlement and the uses to which direct payments may be put. The Equal Lives report called for action to be taken to enable and promote wider access to direct payments for people with learning disabilities (Objective 9, 2005). One concern is that, once the young person is 18, the direct payment can no longer be claimed by the parent and will not be able to be given to the young person if they are not deemed capable of managing it themselves.

Guidance for children with disabilities issued to support the Children Order has a section on transitions which emphasises the need for co-operation and for provision to support the transition process.²⁴ Some but not all of the HSCTs have appointed Transition Officers who will communicate with schools and others and provide advice and assistance to parents and young people during transition. In practice, the level of social care given on the transition to adult services will vary with the needs of the young person and the eligibility criteria used by the HSCT to determine access to services. Some young people we spoke to did not appear to have had any social care assessment and their families reported that they had not had contact with social services in many years. Others had very good relationships with their social workers

²⁴ Children Order: Guidance and Regulations, Volume 5 (Children with a Disability) (1996), Belfast: The Stationery Office.

and had benefited from the advice of the HSCT's Transition Officer. Concern has been expressed that, as young people move to adult social services, re-assessments have associated delays and consequent gaps in provision whilst eligibility to access community care support and the make up of packages are assessed and determined. This might mean that some young people leave school without knowing where they will be moving to, or have to start FE or training after the course has started because of uncertainty about provision. Moreover, parents of young people with mild or moderate learning disabilities can find that their child is no longer assessed as needing a service or the same level of support and they themselves may be faced with difficult decisions about sourcing alternative support and/or care. A particular concern was expressed about the fact that young people who move to adult services when they are 18 may still be at school until they are 19 and that can disrupt the care package: so for example, children's services may provide transport directly from school to respite care and back but that might stop when the child is 18. It was suggested that the move to adult services should coincide with leaving school where the upper age is 19 for example, and not the young person becoming 18.

Leaving school can bring with it additional concerns for parents and carers since it may also mean leaving behind the predictability of the same five-day provision that had been in place since their child started school and that was available during the school term (Pilnick et al 2011). Thus, transition periods may be associated with increased demand for short breaks or respite service provision from parents/carers. Research also suggests that carers of young people with learning disabilities are concerned about having to build a new network of support, both for themselves and around the young person.

Research indicates that successful transitions in social care services necessitate:²⁵

1. Forward planning;
2. Continuity of care, through for example, a designated social worker;
3. Support for families and young people in moving from child focused to adult short break services;
4. Sampling of future short break and residential options;

²⁵ McConkey et al 2011; Bhuamik et al 2011; Hudson 2006; Heslop and Abbott 2007; Perrins and Tarr 1998; Docherty and Reid 2009.

5. Developing skills for independent living and being given the opportunities to use these;
6. Age appropriate day centre activities and provision;
7. Training for staff in day centre settings and support for families as 'enablers' and 'facilitators' of independent living;
8. Greater links and knowledge transfer between children's and adult service planners;
9. Including young people in decision-making processes relating to short break and independent living transitions.

People with learning disabilities are also considered to be at particular risk of abuse and safeguarding concerns, in part due to the need of some people with learning disabilities for services, personal care needs, and/or communication difficulties. While children may be at risk from family members and others known to them, there has been increasing awareness of abuse by professionals and others in positions of trust. For example, within health and social care in 2006 and 2007, reports were published following investigation of abuse of people with learning disabilities in the care of Cornwall Partnership NHS Trust and the Sutton and Merton Primary Care Trust in England.²⁶ The subsequent Healthcare Commission Audit of services in England found that insufficient attention was paid to safeguarding vulnerable people across all aspects of their care.²⁷

In Northern Ireland, a review carried out by RQIA in 2008 of the safeguards in place for children and vulnerable adults in mental health and learning disability hospitals expressed serious concern at the numbers of children being admitted to adult wards and at the work that remains outstanding within HSCTs to ensure all staff receive dedicated training in the areas of child and adult protection. In particular, the review recommended that HSCTs should work in collaboration with the DHSSPS to minimise the numbers of children admitted to adult wards, and ensure that child and adult protection training is provided in accordance with regional guidance, to all staff and volunteers working in mental health and learning disability services (RQIA 2008). Similarly, a review of respite services at Cherry Lodge Children's Home for children with complex disabilities in 2007 highlighted that an eighteen year old was admitted for 'respite' because there was no age-appropriate alternative provision available at that

²⁶ Healthcare Commission and Commission for Social Care Inspection, Joint Investigation into Cornwall Partnership Trust, July 2006; Healthcare Commission, Investigation into the services for people with learning disabilities provided by Sutton and Mersey Care Trust, January 2007.

²⁷ Healthcare Commission, A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England, December 2007.

time. The broader review made a number of recommendations for organisations who commission, deliver and monitor respite provision for children with disabilities, including: the need for regular training in child and vulnerable adult protection procedures; monitoring of procedures, information and reporting systems; and that every effort is made to involve young people and their families in assessments, developing care plans, and reviews.

According to Equal Lives, in Northern Ireland, the majority of school leavers from SLD schools have traditionally been placed in day centres commissioned by health and social care agencies. The IDG report stated that this option was preferred by many parents “because it provides a reliable service in a secure environment, usually with transport to and from the centre”. However, demand for day centre places exceeds supply. Equal Lives estimated that 180 children with severe and profound learning disabilities leave school each year and that, if all were to be accommodated in day centres, an increase of around 20% in places would be required between 2005-2010 with an additional cost of approximately £5.5 million (p.48).

The 2006 IDG report highlighted the inappropriate and inflexible day care provision available for young people with learning disabilities. It noted that there was no stimulus and few opportunities for any type of vocational or life skills training. The IDG also highlighted gaps in ‘transition training’ for independent living. The NI Executive’s response to the Bamford Review (2008) highlights that recurrent funding of £0.9 million was announced in March 2006 from the Children and Young Persons Funding Package for the improvement of day care for young people when they become 18 and are moving from children’s services into adult services. According to the report, around 150 ‘purposeful places’ for young people making the transition into the community have been created (p.41). The report states that these places will be continued and the NI Executive will take steps to improve service delivery across all areas as children move into adulthood. Gaps in day services for young adults aged 18-24 were, however, highlighted by respondents in a 2007 Audit of Day Services in Northern Ireland (DHSSPS 2007).

The recently published Compton Review (2011) of Health and Social Care in Northern Ireland indicates that the diversity and age-appropriate nature of day services remains an issue for people with a learning disability. While there has been progress made in reforming the day centre-based model and providing more community based options, there is further work to be done in this regard. The review proposes the further development of a more diverse and flexible range of age-appropriate day support and respite and short-break services. In spite of this, targets for increasing provision have

not been met: for example, it is reported that the Bamford Action Plan target of 200 new or additional respite packages (2009-2011) to benefit people with a learning disability was reduced to 125 additional respite packages in the DHSSPS Priorities for Action (2010-11) (Children with Disabilities Strategic Alliance (CDSA) 2012).

A recent review of day care provisions across NI found that, while many people enjoyed and benefited from their current day care provision, there were areas identified as in need of improvement (PCC 2011). These included:

- The need for more choice and flexibility in provision.
- An 'information gap' regarding day opportunities and day care services.
- Concern about staffing levels, transport and the reduction in the number of outings from day centres.
- A person-centred approach to day care services and day opportunities, planning around the needs of the individual.
- A lack of opportunities for people with severe and profound disabilities and those with challenging behaviour.

A particular social care issue arises in relation to young people with learning disabilities who are leaving residential care at age 18 which is a requirement in relation to children's homes once the young person is 18. HSCTs are under an obligation to advise, befriend and assist children whom they look after when they cease to be looked after.²⁸ The Care Matters (2007) report identified a range of issues for young people on the transition from care, including the need for support in all aspects of life, including education and health.²⁹ However, the report did not specifically address the challenges faced by young people with learning disabilities whose needs may be more complex again. There appears to be some additional difficulties in ensuring that these young people make a successful and timely transition to alternative accommodation and support arrangements which are appropriate and meet their needs and preferences. Moreover, that staff involved in services for young people with disabilities leaving care need to be equipped to deal with the particular needs of this group.

²⁸ Children (NI) Order 1995, Article 35(1).

²⁹ DHSSPS (2007) Care Matters in Northern Ireland – Building a Bridge to a Better Future, (Belfast: DHSSPS).

There is also concern at the lack of future planning for young people living with family members and people with a learning disability have talked about wanting to leave their family home but needing information, advice and support to help them do so (Mencap 2011).

The NI Executive's response to the Bamford Review report states that DE secured a further £100,000 per annum from the Children and Young People's Fund in 2006/07 and 2007/08 to enhance life skills training in schools and improve self-help and independent living. However, the Children with Disabilities Strategic Alliance Manifesto (2012) noted that there continues to be "limited co-ordinated support across agencies and a lack of tailored services to enable young disabled people to make this transition to independent living" and calls for:

1. A strategic co-ordinated approach which results in empowering young disabled people to become independent, confident adults is urgently needed.
2. Targets across departments to ensure equal opportunity for young disabled people to live independently in all aspects of their life.
3. Investment in age-appropriate accommodation, ensuring that young people with disabilities are supported to live at home or to move to alternative accommodation of their choice.
4. Access to life and work skills training including travel training, money management, and personal safety and relationships.

3.1.3 Summary of Issues of Concern

- Reduced levels of financial and other social care support available to young people and their family carers on leaving school.
- Availability of age appropriate and flexible day services and short break services.
- The need for continuity when the young person becomes 18 while still at school.
- Need for opportunities to build up experience of attending day services while still at school.
- Quality of the educational and lifelong learning opportunities available in day services, including lack of resources and staff with appropriate training.
- Need for greater co-operation and consistency in planning and decision-making across sectors within HSCTs.
- Not all HSCTs have Transition Officers.

- Need for greater transparency of information and support for parents about the real options available, including on the range of accommodation, alternative sources of support, and greater clarity around eligibility/entitlement for services including direct payments and carers assessment.
- Need for support to facilitate transitions to adult residential care and/or independent living.
- Networks of support for parents and opportunities for young people to make new friends.
- Information and support to connect to their local community.
- Advocacy support for young people and family carers.
- Impact on family carers when the person they care for and support do not get support from social care services.

3.2 Health Care

3.2.1 International Standards

Article 24 of the CRC establishes the right to health and health care. The Committee on the Rights of the Child has stated that attainment of the highest possible standard of health as well as access to quality healthcare is an inherent right for all children including children with disabilities. They have emphasised the importance of community-based assistance and rehabilitation strategies when providing health services for children with disabilities. Moreover, States parties must ensure that health professionals working with children with disabilities are trained to the highest possible standard and practice based on a child-centred approach (UN 2006, at para 52). The Committee has stated that States parties should provide health services that are sensitive to the particular needs and human rights of all adolescents, and adolescents with disabilities in particular. Such health services should be: (i) available; (ii) accessible; (iii) acceptable; and (iv) good quality. More generally, the Committee has stated that States parties should, where feasible, adopt a multi-sectoral approach to the promotion and protection of adolescent health and development by facilitating effective and sustainable linkages and partnerships among all relevant actors (UN 2003b, at para 42).

A right to health is also established in Article 25 of the CRPD. States Parties to the CRPD are required to, inter alia, (a) Provide people with disabilities with the same range, quality and standard of health care and programmes as provided to others; (b) Provide those health services needed by persons with disabilities specifically because

of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children; (c) Provide these health services as close as possible to people's own communities, including in rural areas; (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care; and (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

3.2.2 Law, Policy and Practice

The requirement on HSCTs to assess the health and social care needs of young people is discussed above. Once a young person is 18, their health needs are part of the general legal obligations in relation to the provision of health care. There are nominated leads at senior level for mental health and learning disability for both adults and children in DHSSPS, the Public Health Agency, the HSC Board, and each Health and Social Care Trust. The NI Executive's response to the Bamford Review states that commissioners and service providers will need to ensure that there is equity of access to the full range of healthcare provision enjoyed by the general population. It notes that DHSSPS has made a Directed Enhanced Service (DES) for Health Checks for Adults with Severe Learning Disabilities a priority area, given the difficulties adults with severe learning disabilities can experience in accessing health and social care services. However, it does not specify what priority, if any, is given to young people with learning disabilities making the *transition* to adult health and social care services. The CYPSP Outcomes Groups have recently finished consulting about the issues affecting children, young people and their families in each of the five HSCT areas. The responses received from this consultation will inform the actions plans for each area as part of the Northern Ireland Children and Young People's Plan. For example, one of the priorities out for consultation in the Belfast group is: "Supporting those children and young people living in families with complex health problems, mental health problems and/or disabilities". Families of young people we spoke to identified a need for health professionals to be informed about the young person's learning disabilities and to be trained to communicate with young people effectively so that they get the best possible care.

Existing research indicates that people with a learning disability are more likely than the general population to experience poorer physical and mental health, and have significant unmet health needs.³⁰ Research indicates that there is a need for greater attention to be paid to the transition to health and social care services (Kaehne 2011).

Specifically, research suggests that successful transition to adult health services requires:³¹

1. Identification of clear pathways to adult health and social care services at transition stages;
2. Co-ordinated person-centred planning;
3. Integrated professional care;
4. Active engagement of health professionals with transition partnerships;
5. A standard age cut-off for all health and social care services;
6. Addressing differences in eligibility and referral criteria between child and adult health services;
7. A good knowledge transfer infrastructure between child and adult services;
8. Health action planning.³²

Indeed, the consequences of a poor transition out of children's services with lack of continuity and follow-up can have a serious impact for young people as well as additional health service costs (Department of Health 2008). The Department of Health in England produced a Good Practice guide 'Transition: Moving on Well' in 2008 in which it identified 13 key principles of health transition planning.

Discussions held with school principals during this study highlighted concern that services in this context may also be vulnerable to cuts in funding across health and social care. Specific issues which arise in relation to the health of young people with learning disabilities are as follows:

- **Access to Allied Health Professionals.** Equal Lives (2005) highlighted concern among parents that access to the services of Allied Health Professionals reduces upon leaving school. The Children with Disabilities Strategic Alliance noted that

³⁰ See for example, Equal Lives 2005; Mencap 2004, 2007, 2011; DRC 2006; ECNI 2008; Allerton et al 2011; Marshall et al 2003; McConkey, Barr et al 2003; Brown et al 2010.

³¹ Bhaumik et al 2011; Kaehne 2011; McConkey, Barr and Baxter 2007; Ward et al 2003; Department of Health (DH) 2002; DH 2009.

³² The development of a health action plan for all people with learning disabilities was included as a specific target in *Valuing People* (2001), the Government White Paper for learning disability.

disabled young people, including young people with learning disabilities can wait up to 26 weeks from referral to commencement of Allied Health Professional services when entering adult services (CDSA 2012). Parents also report a perceived dip in the level of services. The IDG (2006) noted that “in order to alleviate the difficulties encountered by young people during the transitions period, one option available is to employ a Transitions Officer to deal with the healthcare aspect of the process.”

- **Transition in Hospital Care.** A DHSSPS report into services for disabled children in hospitals acknowledged that: “The transfer of children to adult services can be a source of anxiety to children, parents and families because of the loss of a familiar consultant or nursing staff and fear of the child going unnoticed in the adult world.” (2005, p.44). It found that clear transitional arrangements did not exist within hospitals and highlighted ambiguities about the age at which young people should access adult services. For example, children may transfer to adult wards in acute hospitals at 14; they may transfer from Community Children’s Nursing between 16 and 18 years; they may no longer qualify for children’s respite services at 16 years of age and they may leave school at 16 years (McConkey, Barr and Baxter 2007). The report called for ELBs and HSCTs to establish a regionally agreed protocol to inform the transfer of children and young people to adult hospital or community services which: takes account of age; allows for a flexible transition period; and promotes a coordinated strategy across all disciplines. The 2010 Guidelines on Caring for People with a Learning Disability in Hospital Settings highlights a number of persistent difficulties encountered by people with learning disabilities, their families and staff within general hospital services and acknowledges that particular attention needs to be given at particular transition points such as the transition from general hospital to community services and transitions between child to adult services within general hospitals.
- **Mental Health.** Young people with learning disabilities are much more likely to experience mental health problems (Bamford 2005) and those young people will require a smooth and effective transition from child to adult mental health services. A Review of Child and Adolescent Mental Health Services (CAMHS) published by RQIA in 2011 recommended that operational protocols should be put in place for the seamless transfer of young people from CAMHS to adult services and that there should be routine evaluation of how these arrangements work, ensuring that the views of the young people are collected and considered. A 2011 report by the Bamford Monitoring Group highlighted that young people

had difficulty finding relevant information on mental health services for young people when visiting Health and Social Care Trust websites for the first time and that a considerable amount of guidance was necessary in order for people to find what they were looking for. Standard 56 of the 2011 Service Framework on Mental Health and Wellbeing stipulates that “A learning disabled person with mental health needs should have access to appropriate mental health support for their needs” and includes equity, person-centred, efficiency/effectiveness, and safety as the ‘quality dimensions’ for this standard while Standard 31 addresses transitions to adult mental services for young people generally. Discussions held during this project highlighted concern at the negative impact of transitions on mental health and wellbeing. For example, concern was expressed at the pressure placed on young people in the transition to FE and the difficulty some young people had in coping with new and unfamiliar settings alongside limited support and meeting new people. Indeed the Bamford report A Vision of a Comprehensive CAMH Service (2006) highlighted that an IQ of less than 70 is often seen as a cut off point between CAMH services and learning disability services in some HSCT areas and 55 or 65 in others. Moreover, lack of capacity in specialist CAMH services restricts the services that can be provided to young people with moderate and mild learning disabilities and there is a significant shortfall of staff with the specific competencies to work with young people with learning disabilities who also have with mental health difficulties. As such, the report suggests that children and young people with mild or moderate learning disabilities are more likely to have difficulty accessing appropriate mental health services within either learning disability services or CAMH services due to the debates which occur regarding the cut off points by which services will accept referrals and that young people with severe learning disabilities with mental health difficulties instead access inpatient facilities in a hospital for those with a learning disability (Bamford 2006). The report recommended that specialist mental health services for children and adolescents with learning disabilities should be commissioned as part of specialist mental health services for all children while future severe learning disability inpatient provision should be in community-based child and adolescent specific units. Finally, that key staff should be trained in both learning disability and mental health disciplines to lead development.

- **Sexuality and Relationships Education** Young people with learning disabilities have expressed the need to have appropriate and effective sex and relationship education and may in fact have an additional need to receive it given the increased vulnerability of some to exploitation (Equal Lives 2005). The NI

Curriculum contains provision for health education through the inclusion of ‘personal understanding’ and ‘personal health’ as key elements to be addressed by all learning areas/subject strands, and through the specific requirements contained in the programmes for Personal Development and Mutual Understanding (PDMU) (primary) and Personal Development (PD) (post-primary).³³ While the curriculum requires that all young people learn about the implications of sexual maturity and early sexual activity, individual topics are not statutory.³⁴ Schools therefore have considerable discretion as to what to teach and there are concerns that teachers may not have the training to address the issues effectively. Moreover, while there is no legislative provision permitting parental withdrawal from sex education, schools may be granting these requests on a case by case basis, with a potentially detrimental effect on young people’s right to an effective education.

3.2.3 Summary of Issues of Concern

- Delays, eligibility and referral criteria in accessing adult allied health care services.
- Equality of access to Transition Officers across the five HSCTs.
- Support for children and young people making transitions into and out of acute hospital care.
- Access to appropriate mental health services pre and during transition.
- Need for support and information on the transition to adult mental health services.
- Additional support for young people with a learning disability as they respond to changes in their life.
- Need for age appropriate, tailored sexuality and relationships education for all young people with learning disabilities including those with severe learning disabilities.

³³ Education (Curriculum Minimum Content) Order (Northern Ireland) 2007.

³⁴ Education (Curriculum Minimum Content) Order (Northern Ireland) 2007.

3.3 Support for Families and Carers

3.3.1 International Standards

Article 18 of the CRC obliges States parties to provide appropriate support for parents and carers in bringing up their children alongside the development of appropriate institutions, facilities and services. This should be read in conjunction with Article 5 with respect to parental duties and Article 27 which obliges State parties to support parents in ensuring an adequate standard of living for their children. The Committee on the Rights of the Child has made it clear that children with disabilities are best cared for and nurtured within their own family environment “provided that the family is adequately provided for in all aspects” (UN 2009, at para 41). The types of support highlighted by the Committee include: provision of psychological support that is sensitive to the stress and difficulties experienced by families with children with disabilities; material support in the form of special allowances as well as consumable supplies and necessary equipment, such as special furniture and mobility devices that is deemed necessary for the child with a disability to live a dignified, self-reliant lifestyle, and be fully included in the family and community.

Support services should also include different forms of respite care, such as care assistance in the home and day-care facilities directly accessible at community level (UN 2009, at para 41). Article 23(3) of the CRPD obliges States Parties to provide ‘comprehensive information, services and support to children with disabilities and their families.’

3.3.2 Law, Policy and Practice

The Children (NI) Order 1995 and the Carers and Direct Payments Act (Northern Ireland) 2002 provide for an assessment of the needs of those caring for children with disabilities. On transition to adult services, the HSCT will decide what support and assistance may be given to a young person. If the young person is living at home and ‘receiving a substantial amount of care on a regular basis from another person (who is not a person employed to provide such care),’ it will have regard to the ability of that other person to continue to provide such care on a regular basis.³⁵ The NI Families Matter Strategy (2009) sets out the vision for improving support and services for all

³⁵ Disabled Persons (NI) Act 1989, s. 8.

families, including families of young people with disabilities. Based on a 'whole child' and 'family support' model, the strategy identifies four underpinning themes: relevant, clear and accessible information for parents; access to services; support for parents and families; and 'working together for families and communities', including through multi-agency working. Although transition is not explicitly referred to here, these principles are clearly applicable.

Successful transitions require the active engagement and participation of parents/carers throughout the transition planning process (Carnaby et al 2003; Lynggaard 2002; Beresford 2004; Heslop and Abbott 2007; Ward et al 2003). Key factors associated with successful parental participation include:

1. Involvement in the planning process from the outset;
2. Meaningful participation in transition planning meetings;
3. Named support for families as they adjust to new and unfamiliar structures;
4. Clear channels of communication with professionals;
5. Clarity with respect to the roles and responsibilities of different agencies;
6. Provision of accessible and comprehensive information on available placement options;
7. Provision of accessible and comprehensive information on associated issues such as social security, transport and short breaks.

Families of young people with learning disabilities provide care and support well beyond what is normally expected and over a longer period of time, acting, at various junctures, as an advocate, educator and/or communication facilitator (Equal Lives 2005).

However, the practical and emotional support provided to families, particularly at times of transition, is fragmented and patchy across Northern Ireland (CDSA 2012, Equal Lives 2005). Parents of young people with learning disabilities are often very anxious about their child's future (PCC 2011). Concern has been expressed at: the extent to which parents are able to meaningfully participate in transition meetings; at the lack of information and advice provided during the transition process; and at the high numbers of professionals participating in these meetings and the daunting experience this can subsequently create for parents (Equal Lives 2005; IDG 2006). The IDG recommended that ELBs develop an information leaflet for both pupils and parents to ensure that they are aware of the support available from the Education Transitions Co-ordinators and how this links with advice and support from other statutory agencies. Some of the families of young people we spoke to had not received any information or advice on the services available to them and their child on leaving school. All parents spoke about the additional stress and anxiety they felt as their child approached school leaving age and

the impact that could have on their health and on other family members. The Children with Disabilities Strategic Alliance has recently argued that the support needs of young people with disabilities and their families at transition need to be prioritised within future funding for family support services.

3.3.3 Summary of Issues of Concern

- Need for information and advice for parents and carers.
- Equal access to support for families across Northern Ireland.
- A policy which reflects a rights based approach rather than a deficit model of support.
- Parents as partners in the process.

Chapter 4: Social Security, Leisure and Transport

While the areas of social security, leisure and transport were not included in NICCY's original terms of reference for the study, these were identified as important by the research team during the course of the project. In particular, the inclusion of these areas are reflective of the interdependent, indivisible and holistic nature of children's rights more generally. For example, it was clear during discussions with stakeholders for this research and a review of the literature that decisions relating to transition planning and post-16 placement had direct implications for, and were impacted by, issues relating to social security, leisure and transport, and as such could either enhance or complicate transitions to adult services in education, employment and training, and health and social care.

4.1 Social Security

4.1.1 International Standards

Article 28 of the CRPD recognises the right of people with disabilities to social protection without discrimination on the basis of disability while Article 26 of the CRC recognises the right of children to benefit from social security. Article 26(2) specifies that the benefits should, "where appropriate, be granted, taking into account the resources and circumstances of the child and persons having responsibility for the maintenance of the child, as well as any other consideration relevant to an application for benefits made by or on behalf of the child."

4.1.2 Law, Policy and Practice

Social Security legislation in Northern Ireland, whilst different, has traditionally adopted arrangements in place in England and Wales through the principle of parity. Currently, assistance will be provided to parents who are on social security benefits through an enhanced premium when a young person has a disability (which is defined as being in receipt of Disability Living Allowance (DLA)). Once the young person leaves full-time education at sixteen or eighteen, they are entitled to benefits in their own right. Entitlement will depend on the individual person and their needs. However, a recurrent issue in the literature is the disincentive for young people to undertake more than part-time hours because of the adverse impact on benefits (PCC 2012). The desire of young

people with learning disabilities to move into employment is often offset by concern at the loss of benefits in so doing; acting as a barrier to labour market participation (Gillan and Coughlan 2010; Gosling and Cotterill 2000). Some part-time employment schemes may be more appealing to people with learning disabilities rather than full-time work as they may retain some or all of their welfare benefits (Jenkins 2002). Indeed, the complex rules of the existing benefits system can serve as a disincentive for young people with learning disabilities entering the labour market, thus making continued training more likely (Booth 1997). McLaughlin et al (2001) argue that young people with learning disabilities and their families need to be reassured that welfare benefits will not be lost if a supported employment opportunity is not successfully sustained. Research indicates that among the issues young people and their parents also wanted information about in the transitions process was benefits (Heslop et al 2001; Hudson 2006).

In Northern Ireland, the IDG report (2006) identified similar concerns among parents with respect to the 'benefits trap'. These concerns were reiterated in the Equal Lives report (2005). The 2009 and 2012 CDSA manifestos called for children and young people with disabilities and their families to be provided with easier and targeted access to independent advice and information on grants, benefits and other sources of financial help that are available, and associated claim forms made more accessible and less complex. Families we spoke to stressed the need for clear, accessible and accurate information. For example, one parent had been told that her child could continue to receive Educational Maintenance Allowance (EMA) and the FE allowance, only to be told later that this was not possible. In addition, that key benefits for children and young people with disabilities need to be index linked and to reflect the true costs of disability. The complexity of claiming benefits particularly during the transition stage was further highlighted by the PSI Sub Group reports. Other issues considered by the sub group included the lack of awareness amongst young people with disabilities on the benefits which can be claimed and confusion over the loss of benefits when attending FE or entering work (PSI 2009).

In terms of assistance with social care, the major benefit currently is Disability Living Allowance (DLA) which can provide financial assistance with costs of care and assistance. 2.1% of all DLA claimants are aged between 16-19, while 7.5% of all awards have been made to people with 'learning difficulties'³⁶. The number of requests for review of decisions across all claimants increased from 14,597 in 2001/02 to 19,317

³⁶ Department for Social Development, Disability Living Allowance, Summary of Statistics, 28 February 2011.

in 2007/08, falling to 14,180 in 2010/11.³⁷ Under the proposed welfare reform legislation, this is being replaced with a new benefit called a Personal Independence Payment (PIP) which will be subject to annual review. Moreover, it is currently proposed to extend the qualifying period from three months to six months. Concern has been expressed that the existing DLA assessment process is too medically based and focused on identifying levels of impairment rather than experiences of disabling barriers, and that this may be reinforced rather than challenged by the new PIP assessment process (Morris 2011). Indeed, the Joint Committee for Human Rights has expressed concern that there is a risk of retrogression of the UK's obligations under Article 19 of the CRPD (the right to independent living) as a result of cumulative effect of spending cuts and welfare reform (JCHR 2012). Government figures suggest that 500,000 fewer people could receive the new PIP in comparison with DLA.³⁸

4.1.3 Summary of Issues of Concern

- Financial disincentives to working more than sixteen hours a week.
- Need for accessible information about entitlement and extra support for the process of claiming benefits.
- Concerns about the impact and complexity of proposed welfare reforms and the move to a system designed with adults in mind.

4.2 Leisure

4.2.1 International Standards

Article 31 of the CRC establishes the right of children to leisure, play and culture. In General Comment 12, the Committee on the Rights of the Child has said that children should be consulted regarding the accessibility and appropriateness of play and recreation facilities. Further, that "Very young children and some children with disabilities, who are unable to participate in formal consultative processes, should be provided with particular opportunities to express their wishes." (UN 2009, at para 115). In General Comment 9, the Committee has emphasised that "Children with disabilities should be provided with equal opportunities to participate in various cultural and arts activities as well as sports" (UN 2006, at para 71).

³⁷ No further breakdown is provided.

³⁸ Department for Work and Pensions, Personal Independence Payment: assessment thresholds and consultation, January 2012, <http://dwp.gov.uk/consultations/2012/pip.shtml>

The Committee on the Rights of the Child has emphasised that access to information and means of communication, including information and communication technologies and systems, enables children with disabilities to live independently and participate fully in all aspects of life (UN 2006, at para 37). In particular, children with disabilities should also be provided with the appropriate technology and other services and/or languages, which would enable them to have access to all forms of media.

Article 1(h) of the CRPD requires States Parties to provide accessible information to people with disabilities about mobility aids, devices and assistive technologies as well as other forms of assistance, support services and facilities. Similar further provisions are contained in Article 21 of the CRPD ‘Freedom of expression and opinion, and access to information’.

4.2.2. Law, Policy and Practice

The Disability Discrimination Act (DDA) 1995 requires service providers to make ‘reasonable adjustments’ to ensure access to services. This includes public amenities such as parks and play and leisure facilities. The Special Educational Needs and Disability (NI) Order 2005 extends DDA requirements to cover any provision that takes place on school premises, including school sports, clubs and activities. In terms of policy, the Play and Leisure Policy and Implementation Plan seeks to improve play and leisure opportunities for all children and young people in Northern Ireland including young people with disabilities up to the age of 21. The policy does not mention transitions or learning disability specifically, although it clearly includes those undergoing transition up to the age of 21. The Implementation Plan sets out a number of relevant actions including:

- Promoting the use of play services by young people with disabilities;
- Informing on availability and promoting use of Door-to-Door transport in urban areas for children and young people with disabilities so that they can access their local play and leisure spaces safely.

The Strategy for Sport and Physical Recreation in Northern Ireland, 2009–2019 does not specifically address transition or learning disability, but includes as actions:

- Commitment to deliver at least a 6% increase in participation rates in sport and physical recreation among people with a disability by 2019;

- Increased opportunities for under-represented groups, including people with disabilities;
- The appointment of 18 Disability Sports Development Officers delivering increased opportunities for people with a disability to develop and sustain their involvement in sport and physical recreation.

It is recommended that the social, leisure and communication needs of young people with learning disabilities should be part of forward transition planning (Heslop and Abbott 2007). Reynolds (2002) highlights the role of social and leisure activities as an important source of self-esteem, choice, stimulation and support for people with learning disabilities and as a major forum in which peer relationships are forged; an issue of particular significance for young people with learning disabilities who are disproportionately reliant on their immediate family for social activities (Brewster and Coleyshaw 2010) and for whom transition can bring with it particular anxieties about moving away from existing school-based social networks. Access to leisure facilities and opportunities to associate with their peers was one of the most important issues to the families of young people to whom we spoke.

Many of the young people we spoke to were enjoying a range of leisure opportunities including participation in the Duke of Edinburgh awards and the Special Olympics. However, this was not always the case and seemed to vary from area to area. Transport costs, distance from home, unavailability or lack of leisure opportunities and a lack of staff for one-to-one support are commonly seen as limiting leisure choices (Reynolds 2002; Beart et al 2001; Thompson, Taylor and McConkey 2000). Moreover, that people with learning disabilities can encounter difficulties in accessing community and mainstream leisure facilities, in part due to negative public perceptions of and attitudes towards people with learning disabilities and resource restrictions (Reynolds 2002) and the lack of opportunity to do so (Thompson, Taylor and McConkey 2000). Indeed much of the literature notes that 'leisure' for children and adults with learning disabilities is primarily home-based and of a solitary nature (for example, Thompson and Emira 2011; Thompson, Taylor and McConkey 2000). Beart et al (2001) suggest that people with mild to moderate learning disabilities and relatively good communication skills are more able to access community leisure opportunities than people with more severe learning disabilities or poorer communication abilities. For the latter, the key means of accessing leisure opportunities was often through day centres and were rarely integrated.

Limited attention has been accorded to the particular issues and positive practice associated with the provision of leisure for young people with learning disabilities at

transition. More generally however, Thompson and Mahmoud suggest that, in addition to strengthening staff training, providing better information, improving transport and support systems, there is a need for a “dedicated and consistent strategy that builds and sustains trust and continuity” (2000, p.70). Indeed, they suggest that the lack of opportunities potentially “leads to the reduction of social capital in the form of life chances, job opportunities and hinders the transition into adulthood.” (p.71).

4.2.3. Summary of Issues of Concern

- Equal access to age appropriate leisure opportunities.
- Support on the use of online tools.
- Individualised support to take part in age appropriate activities enjoyed by other young people.
- Information and support for parents on supporting their son/daughter in accessing and participating in leisure opportunities.

4.3 Transport

4.3.1 International Standards

Article 9 of the CRPD requires States Parties to take measures to ensure people with disabilities have access, on an equal basis with others, to “the physical environment, to transportation, to information and communications..., and to other facilities and services open or provided to the public.” The measures to be taken should include both the identification and elimination of obstacles and barriers to accessibility.

4.3.2. Law, Policy and Practice

The Disability Discrimination Act, as amended by the Disability Discrimination (Transport Vehicles) Regulations (Northern Ireland) (2006) makes it unlawful for transport providers to discriminate against people with disabilities of all ages. This came into force in January 2010. There is no specific obligation to provide transport training for people with learning disabilities.

The Accessible Transport Strategy (2005) seeks: “To have an accessible transport system that enables ... people with disabilities to participate more fully in society, enjoy greater independence and experience a better quality of life.” Among the designated actions in the 2012-2015 action plan are commitments to:

- Explore how information provision on transportation issues can be improved for people with learning disabilities;
- Review Department for Regional Development staff training to ensure that its contents cover the needs of people with learning disabilities;
- Work with charities, schools and education authorities to distribute the Travel Safe guide to people with learning disabilities to encourage independent travel;
- Undertake research into the transport needs of younger disabled people and consider outcomes;
- Undertake research into the transport needs of people with Autism and consider outcomes.

Transportation is a big issue in transition planning, restricting choice of options if parents are unable to support a student in reaching a pick-up point for a service out of their immediate catchment area (Cameron, Lewis et al 2003). McLaughlin et al (2001) report how choice of placements post-secondary education were often based on what was locally available to them so that transport problems did not arise. Families we spoke to expressed concern about transport arrangements after school since their children had previously received a school bus or taxi from door to door or had been transported by car by their parents. Transport provided through HSCTs (e.g. to FE or day centres) can be a case by case decision. This can limit the choice of placements which are available to some young people. For other young people, however, convenience of placement was important as this gave them independence in that they could undertake uncomplicated journeys without needing assistance or reliance on expensive means of transport. The Valuing People Delivery Plan (2009) reports that the key issues surrounding transport for people with learning disabilities relate to accessibility, information and the attitude of some staff towards people with learning disabilities.

In Northern Ireland, the IDG report (2006) recognised the challenges facing those reliant on transport to enable a transition to adult life as well as improving social inclusion. However, transport issues were considered to be beyond the remit of the IDG. In 2005, the Equal Lives report recommended that: “[The] Department of Education and Department of Health, Social Services and Public Safety should ensure that young people with a learning disability are equipped with skills to use public transport where possible through appropriately targeted independent travel training programmes. Where possible these should become part of the curriculum and continuing education plans for young adults.” A 2008 ETI report found that very few of the schools surveyed made provision for training in independent travel. This gap was considered by a majority

of stakeholders to be an important factor in ensuring that work and post-school placements were successful. Young people to whom we spoke had benefited greatly from graduated travel training but their families felt there was still a need for training for staff in public transport for such times as unexpected issues (cancellations, fare changes) arose. A travel guide for people with learning disabilities has now been produced. Similarly, the PSI report on Disability (2009) recommends that the Education and Skills Authority produces appropriate materials to support a Travel and Road Safety Skills programme for young people with disabilities and that youth organisations should be encouraged and supported to run independent travel initiatives for young people with disabilities.

4.3.3. Summary of Issues of Concern

- Need for greater transport training opportunities, independent travel initiatives and consideration of transport links.
- Accessible information about times of public transport.

Chapter 5: Summary and Conclusions

Young people with learning disabilities encounter significant difficulties on transition from school and from child to adult health and social care services and this can be a cause of significant stress and anxiety for them and their parents. The issues are not, however, unknown to policy-makers and practitioners. In fact, there has been a significant amount of attention given to the area in policy and research in the last ten years. This has resulted in some significant improvements in provision, including the appointment of Transition Co-ordinators in all ELBs and in some HSCTs. Nonetheless, in spite of the widespread acknowledgement of the issues impacting on young people with learning disabilities and their families, major concerns remain. The first relates to the general availability, adequacy and appropriateness of provision for young people with learning disabilities in all areas, including education, social care, health and leisure, and the need to join up planning and provision. A recurrent theme in the literature and in the views of the teachers, parents and young people we spoke to was the lack of equality of treatment of these young people at a critical time in their lives. Provision for young people appears to vary considerably across services and across regions. In addition, there are significant, cross-cutting issues, all of which have been identified in previous research and policy, yet remain largely unchanged in practice. Each of these is significant from a child rights perspective and are summarised below.

5.1 Integrated Planning

The Committee on the Rights of the Child has emphasised the need for appropriate co-ordination of services for children with disabilities to ensure that their needs are addressed effectively (UN 2006, at para 7). A widely acknowledged and recurring issue is the need for an integrated planning service between education and health and social care. While there have been efforts to improve communication and co-operation between education and health and social care, there are, in effect, two separate planning and delivery processes for transition which often occur at different points in time in a young person's life. Access to education and/or training post-school can be dependent on access to social care and support and there is limited influence and control in the education sector when key decisions are being made. In view of this, there have been repeated calls for an integrated multi-agency planning process for transition. An inter-departmental action plan on transitions was to be 'considered and developed' under the auspices of the Special Educational Needs Sub Group of the Ministerial Sub

Committee on Children and Young People by May 2009. However, there is no evidence that such an action plan has yet been developed. The issue is currently being considered by the regional Transitions Sub Group of the CYPSP.

5.2 Person-Centred Planning

Article 3 of the CRC requires children's best interests to be a primary consideration in all matters affecting them. A recurring theme in the policy and research literature is the need for person-centred planning across the transitions processes. There is a clear sense that decisions about education and health and social care are often determined by what is available rather than what is in the best interests of the young person and there is little evidence that they get support to ensure their voice is heard. Options are seen to be limited, with many young people falling into one of two categories: those who can attend FE and those who will go to day care. While there is a demand from parents and young people for more flexible packages (for example, some days at FE and some in day care), these are seen to be more difficult to organise and maintain. Moreover, young people have emphasised that they would like the transition processes to be positive experiences, focusing on what they can do rather than what they cannot.

5.3 Consistency in Provision across NI

Article 2 of the CRC requires provision to be made for all young people with disabilities without discrimination. However, across education, health and social care, there appear to be many gaps in provision and access to planning and services. A key gap from a legal perspective is the fact that the statutory duty to plan for transition is currently only available to young people who have statements of special educational need. Even then, practice varies widely from area to area. While all ELBs have Transition Officers, not all HSCTs do and there continues to be variation in the age at which young people have to leave MLD schools. Moreover, the opportunities available to young people in terms of FE, day care, and health and social care provision vary considerably from area to area, with access difficulties compounded by the lack of suitable transport arrangements, particularly for young people living in rural areas. There is a need for a mapping of existing services across Northern Ireland to identify key gaps in provision and to ensure equality of access to appropriate services.

5.4 Access to Information

Articles 12 and 13 of the CRC give young people the right to seek and receive information which will enable them to participate in decision-making and to make clarified choices about their futures on transition. Parents also have a right to receive support in raising their child (Article 18 CRC). The systems of planning for transitions are complex and the opportunities for young people after they leave school are diverse and may require negotiation. In order to be able to make informed decisions about what is the young person's best interests, information should be accessible and readily available, preferably in a single source. Parents and young people alike have concerns about the absence of accessible information to enable young people to make effective and appropriate transitions.

5.5 Participation of Young People in Decision-Making

Article 7(3) of the CRPD requires States Parties to ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right. Outside of the Children (NI) Order 1995, there is no statutory obligation on a public body to take young people's views into account in the decision-making processes around transition, although it is emphasised in guidance such as the Code of Practice on SEN. Moreover, the extent to which it is happening in practice in a meaningful way is unknown. However, it has been suggested that young people's views are not routinely sought and taken seriously in the transition processes. The Committee on the Rights of the Child has recognised that both children with disabilities and adolescents can face particular barriers in the realisation of this right (UN 2006, at para 32). The Committee has made it clear that children should be provided with whatever mode of communication they need to facilitate expressing their views (UN 2009, at para 115). Furthermore, States parties should support the training for families and professionals on promoting and respecting the evolving capacities of children to take increasing responsibilities for decision-making in their own lives (UN 2006, at para 32) as well as "continue and strengthen their efforts to take into consideration the views of children with disabilities and facilitate their participation in all matters affecting them within the evaluation, separation and placement process in out-of-home care, and during the transition process." (UN 2006, at para 48).

The transitions that young people make from school to further education should be a time of excitement and opportunity, a time to become more independent. For young people with learning disabilities and their families, this is often not the case. Rather, it can be a time of stress and uncertainty and a period when young people and their families are anxious at the possible loss of education, social care and health services which are currently in place. These young people have an equal right to effective education, to health care and to social care and support for them and their families which will enable them to develop to their full potential. While the issues impacting upon this have been well rehearsed in recent years, frustrations remain at the lack of progress and there is still much to be achieved for this disadvantaged and sometimes vulnerable group of young people. As the issue is currently under review in the CYPSP groups, in particular the group on transitions of young people with disabilities, there is at present a significant opportunity to support this work and to highlight the shortcomings in existing law, policy and practice from a child rights perspective as well as to provide information and guidance as to what a rights-based level of provision requires in this area.

5.6 Recommendations

5.6.1 Education, Training and Employment

There is a need for:

- Better and more consistent transitions planning and support.
- Statutory obligations to provide transition planning for all young people with learning disabilities and not just those with statements (or CSPs).
- A legal obligation to take young people's views into account in transitions planning.
- Involvement of parents in the transitions process.
- Consistency across ELBs in age at which a young person has to leave MLD schools.
- Information and support for young people and their families about the transitions process and choices on leaving school.
- Greater communication and co-operation between education and health and social services.
- Appropriate and accessible post-school educational opportunities with real options for progression and lifelong learning opportunities.
- Opportunities for work experience while in school.

- Personal support for young people when they are settling into FE.
- A statutory obligation to make provision for young people with learning disabilities generally as well as on transition into FE and from FE to employment.
- Provide a way of challenging decisions about FE provision.
- Consistency across Northern Ireland in terms of transition support and supported employment opportunities.
- Targeted employment interventions.

5.6.2 Health and Social Care

There is a need for:

- Age appropriate and flexible day services and short break services.
- Opportunities to build up experience of attending day services while still at school.
- The need for continuity in the health and social care provision when the young person becomes 18 while still at school.
- Good quality, resourced, educational and lifelong opportunities in day services.
- Greater co-operation in planning and decision-making across HSCTs.
- Greater transparency of information and support for parents about social care options available including on the range of accommodation, alternative sources of support and eligibility for services.
- Advocacy support for young people and their family carers.
- Equality of access to Transition Officers across the five HSCTs.
- Support for children and young people making transitions into and out of acute hospital care.
- Support to facilitate transitions to adult residential care and/or independent living.
- Support and information on the transition to adult mental health services.
- Age appropriate, tailored sexuality and relationships education.
- Information and advice for parents and carers on the types of family support available.
- Equal access for support for families across Northern Ireland.

5.6.3 Social Security, Leisure and Transport

There is a need for:

- Support networks for parents and opportunities for young people to socialise.
- Accessible information about entitlement to benefits.
- Support for the process of claiming benefits.
- Information and support to connect to the local community.
- Equal access to age appropriate leisure opportunities.
- Support on the use of online tools.
- Individualised support to take part in age appropriate leisure activities.
- Information and support for parents on supporting their son/daughter in accessing and participating in leisure opportunities.
- Opportunities for transport training and independent travel initiatives.
- Accessible information about public transport.
- Training on meeting the needs of young people with learning disabilities for staff in public transport and leisure services.

Appendix A

Table of Post-Primary Learning Disability Schools in Northern Ireland by Type, ELB and Leaving Age

School	Area	Learning Disability	School Leaving Age
St Gerards' Education Resource Centre	BELB	MLD	18
Park Education Resource Centre	BELB	MLD	19
Rostulla Special School	NEELB	MLD	17
Beechlawn Special School	SEELB	MLD	16
Killard House Special School	SEELB	MLD	16
Longstone Special School	SEELB	MLD	16
Belmont House	WELB	MLD	17
Knockavoe School and Resource Centre	WELB	M/SLD	19

Erne Special School ³⁹	WELB	MLD	19
Arvalee School and Resource Centre	WELB	M/SLD	19
Rossmar Special School	WELB	M/SLD	19
Glenveagh Special School	BELB	SLD	19
Hillcroft Special School	NEELB	SLD	19
Riverside School	NEELB	SLD	19
Sandelford Special School	NEELB	SLD	19
Roddensvale Special School	NEELB	SLD	19
Castletower Special School	NEELB	SLD	19
Kilronan Special School	NEELB	SLD	19
Knockevin Special School	SEELB	SLD	19
Parkview Special School	SEELB	SLD	19

³⁹ An amalgamation of Erne Special School and Elmbrook Special School was proposed in 2011.

Tor Bank Special School	SEELB	SLD	19
Clifton Special School	SEELB	SLD	19
Ceara Special School	SELB	SLD	19
Rathore Special School	SELB	SLD	19
Sperrinview Special School	SELB	SLD	19
Lisnally Special School	SELB	SLD/PMLD	19
Elmbrook Special School	WELB	SLD/PMLD	19
Foyleview Special School	WELB	SLD	19

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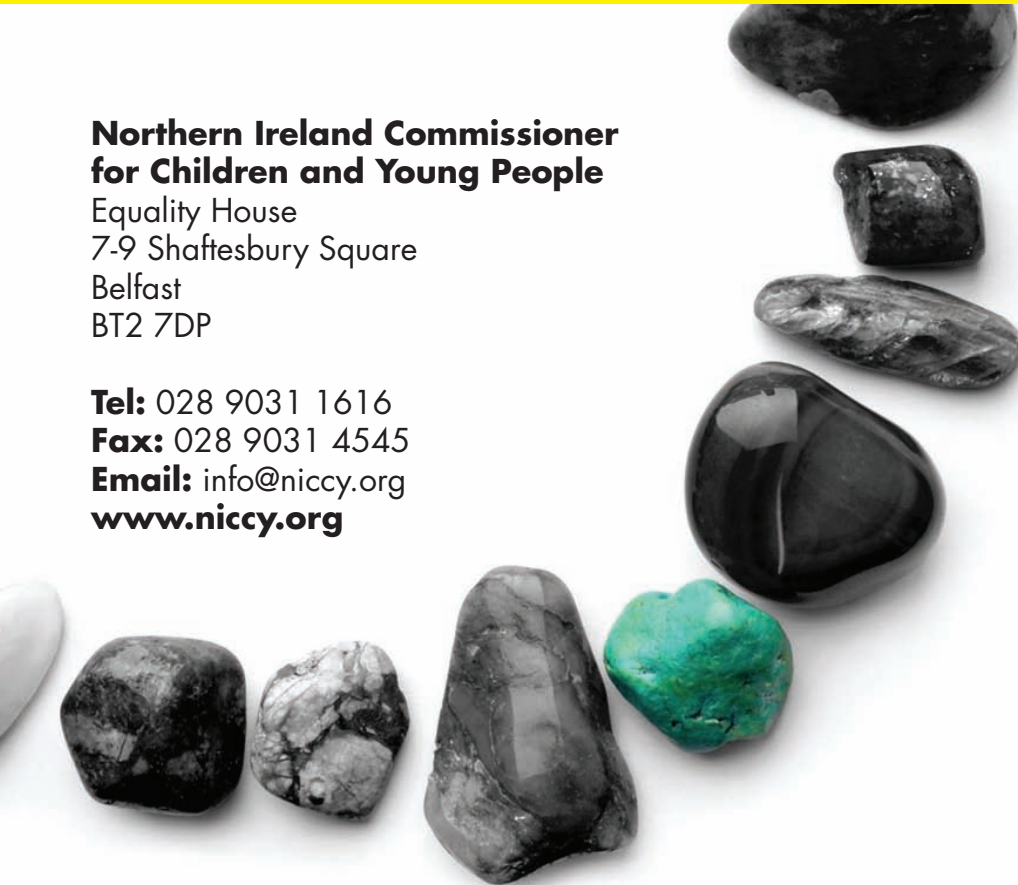


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