

**A Review of the Legislative and Policy Context in relation to
Looked After Disabled Children and Young People in Northern
Ireland.**

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Executive Summary

Recent decades have seen rapid developments in legislation and policy in Northern Ireland (NI) relating to disabled children and adults. These can be located in three key areas:

- Rights based legislation that either relates to all people, all children and/or all disabled people;
- Child care legislation and policy that relates to all children; and
- Disability and mental health legislation and policy that relates to all people with disabilities or mental health needs or people with specific types of disability or mental illness.

Attention to disabled children, including those in care, is largely subsumed within a broader policy focus on disability or children generally as there is no one overarching piece of legislation or policy that relates solely and specifically to all disabled children and/or disabled children in care. There have, however, been developments in legislation and policy which reflect the growing recognition of the complex, interwoven, and previously overlooked needs of this vulnerable group of children and young people and which impact on service expectations and responsibilities.

In terms of defining the population of disabled looked after children, the present study has drawn on the most recent definition of disability provided by the *UN Convention on the Rights of Persons with Disabilities* (United Nations, 2006:4). This states that ‘Persons with disabilities include those who have long-term physical, mental, learning or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’ This means that law and policy relating to looked after children with physical, learning or sensory disabilities as well as those mental health needs are included within this review.

The following five overarching themes are consistently evident throughout the range of documents reviewed, from international human rights instruments to domestic legislation and policy.

- A central underpinning principle which directly impacts on disabled children and young people is that of equality, alongside a focus on social inclusion and anti-discrimination. This is evident both in the spirit of documents as well as in practice guidance and policy recommendations.
- The ‘whole child’ model is a key tenet of child and family policy, underlining the interactive and diverse factors that impact on disabled children’s lives which exert a combined but varied influence on child development, well being and upbringing.
- The family is emphasised as having a central role in children’s lives and documents highlight the foundational impact of family circumstances and wellbeing on children’s upbringing. Whilst the family is recognised to be of central importance, the best interests of the child are also emphasised, and it is noted that the family may not always be the most beneficial environment for all children.
- In terms of service style, common themes within the legislation and policy documents include early identification of need and timely intervention, multi-agency working and person-centred service provision. These approaches to service delivery are identified as increasing the potential to produce improved outcomes for children and young people.
- The importance of seeking the views of children, young people and their families is enshrined in human rights instruments and is a central feature of legislation and policy documents. It is highlighted as a requirement in the provision of services to children and young people, and the need to make suitable adjustments to enable those who do not use speech to communicate is emphasised.

The above themes can be found across the range of documents reviewed; that is those focused on health, social care and education. There is a high degree of consistency in approaches across the range of disability, mental health and children's policy. However, looked after disabled children and young people do not feature strongly in the spectrum of policy and legislation reviewed. Consideration of law and policy relating to this population requires a read across a range of documents and policy areas. There is a

danger, therefore, that their particular needs and experiences may be ignored and could require more focused and holistic consideration in current policy.

The documents reviewed and reported on here are grouped according to type. Chapter 2 focuses on relevant international human rights documents. The principles underpinning the notion of human rights are enshrined in global policy which guides and influences the production of national legislation and policy.

In an international context three rights frameworks are of particular relevance: the *European Convention on Human Rights (ECHR) (1953)*; the *United Nations Convention on the Rights of the Child (UNCRC) (1989)*; and the *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006)*. The first of these, the *ECHR (1953)*, establishes fundamental human rights principles, which are applicable to both adults and children. Whilst the human rights detailed in general instruments are recognised as applicable to all individuals, those who are particularly vulnerable to discrimination are given specific consideration by the United Nations. Children, given their age and need of care and protection are one such group. The *UNCRC (1998)* details human rights and protections with specific reference to children. The rights of people with disabilities are also addressed in a bespoke human rights instrument, the *UNCRPD (2006)* which is equally applicable to both adults and children and aims to address the rights of disabled people that are not directly covered by other human rights instruments.

Chapter 3 of this report focuses on important rights-based documents that feature in the Northern Irish legislative landscape. The *Human Rights Act (1998)* enables individuals to have greater access to challenge rights violations outlined in the ECHR by enabling cases to be heard in UK courts. The *Northern Ireland Act (1998)* established the Equality Commission NI whose role is to oversee discrimination and equality law. Central to protections for disabled people is Section 75 of the *Northern Ireland Act (1998)* which imposes statutory obligations on public bodies to promote equality of opportunity between disabled and non-disabled people. The *Disability Discrimination Act (DDA) (1996)* aims to eliminate discrimination on the basis of disability and promote equality of opportunity. The amendments to the DDA (1996) introduced by the *Disability*

Discrimination Order (NI) (DDO) (2006) broaden the definition of disability and require public bodies to promote positive attitudes towards disabled people and develop strategies to broaden their participation in public life. This legislation provides overarching mechanisms through which equal access to rights by all people are enabled and supported.

Chapter 4 focuses on Northern Irish legislation that has a specific focus on childhood disability. Although dating back several decades, the *Chronically Sick and Disabled Persons (NI) Act (1978)*, the *Disabled Persons (NI) Act (1989)* and the *Mental Health (NI) Order (1986)* have continued salience as they emphasise assessment of need and provision of services to meet identified needs rather than a one size fits all model of service provision. The *Carers and Direct Payments Act (2002)* further extends a needs based approach with the introduction of direct payments and carers' assessments. Although proposed changes to welfare benefits brought forward in the *Welfare Reform Bill (under review)* are likely to impact on the financial situation of disabled young people as well as parents of disabled children. The *Autism Act (2011)* broadens the definition of disability outlined in the *Disability Discrimination Act (1996)* enabling people with autism to have greater access to services and benefits, as well as instructing government departments to develop a strategy and service plan for people with autism.

The *Children (NI) Order (1995)* is the primary statute regulating the care and protection of children. It endorses the view that children are best cared for by their families however, provides guidelines and regulation for state intervention in the care of children where they are at risk of harm. A central principle of the Children Order is the concept of 'best interest' where the welfare of the child is central to decision making. The associated Guidance and Regulations and subsequent *Children (1995 Order) (Amendment) (Children's Services Planning) Order (NI) 1998* address statutory planning processes and requirements in relation to, looked after children and disabled children. The *Children's Homes Regulations NI (2005)* guide process and practice in relation to the welfare of children and the management of children's homes. The *Children (Leaving Care) Act (NI) (2002)*, *Children (Leaving Care) Regulations (NI) (2005)* and *Leaving and Aftercare: Volume Eight Guidance and Regulations (DHSSPSNI, 2005)* provide detailed guidelines and

regulation in relation to young people who are leaving care. Finally, the Standards for Leaving Care Services in NI (DHSSPSNI, 2012e) draw on the outcome statements from the 10-year children's strategy to establish core standards for services aimed at supporting young people leaving care.

Chapter 5 reviews four overarching documents which provide strategic direction to contemporary health and social care policy in NI: *Our Children, Our Young People, Our Pledge (2006)* 10-year children's strategy aimed at improving outcomes for children and young people; *Transforming Your Care (2011)* review of health and social care in NI; *The Child Poverty Strategy (2011)* which presents a strategic framework for eradicating child poverty in NI by 2020 and the *Strategy to Improve the Lives of Disabled People (2012)*.

The focus of chapter 6 is the review of documents which are attentive to child and family policy in NI, with a particular focus on their relevance to disabled and looked after children. *Care Matters (DHSSPSNI, 2007)* is a strategic document setting out a framework for the delivery and development of child and family services. The following year *Understanding the Needs of Children in Northern Ireland (UNOCINI) (2008)* was introduced to ensure a single assessment framework for identifying children's needs. It too is underpinned by the whole child approach and includes specific guidance in relation to assessing need across a range of pathways. *Families Matter (DHSSPSNI, 2009)* focused on the child within the context of the whole family and is attentive to the prevention of family breakdown and a whole child, a family-centred approach, identifying the family as the best environment in which to raise children, if it is in their best interests.

The *Healthy Child, Healthy Future (DHSSPSNI, 2010)* strategy outlines a health promotion programme targeted at all children in NI including looked after and disabled children. It places considerable emphasis on the role of parents and families in the promotion of good health and the prevention of illness. The *Children and Young People's Plan 2011-2014*, provides an integrated, cross-sectoral approach to children's services planning and development. It adopts a rights framework and strongly advocates for the views of children and young people are included in planning and decision-making processes. Both of these documents emphasise early intervention, prevention and joined up services.

Finally, the RQIA (2013) reports on *Community Services for Children with a Disability and Safeguarding Children and Vulnerable Adults in Hospitals* outline the findings of a review of community services and an inspection of safeguarding practice for those residing in mental health and learning disability hospitals. These reports highlight good practice and areas where improvements are required, including issues relating to the placement of children in such hospital settings.

Chapter 7 is attentive to key disability and mental health policies in NI with a particular focus on the sections relevant to children generally or looked after children specifically. A key policy driver in this area is known as '*The Bamford Review*'. It includes the distinct policy documents discussed below, namely the *Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland (2005)* and *A Vision of a Comprehensive Child and Adolescent Mental Health Service (2006)*. The *Equal Lives* report is relevant to both children and adults with learning disabilities. Foundational principles include a right to citizenship, the promotion of social inclusion and empowerment, collaborative working and personalised support to individuals. The report details a range of objectives and recommendations which aim to improve the lives of people with learning disabilities.

In relation to mental health, the Bamford report *A Vision of a Comprehensive Child and Adolescent Mental Health Service (CAMHS) (2006)* outlines guidance for the development of a responsive, integrated CAMHS with the aim of safeguarding the mental health of children and young people. The vision described recommends the promotion of mental health, strategies to prevent the development of mental ill health and accessible and effective treatment of those with mental health needs.

In response to the strategic vision laid out in the Bamford reports the DHSSPSNI developed an *Action Plan for Delivering the Bamford Vision 2009-2011*. This cross-departmental plan underlines a commitment on behalf of the NI Executive to protect and preserve the mental health of the population as a whole, to promote better mental health and to improve the lives of people with learning disabilities or mental health needs. The plan includes specific actions and target dates for their completion, which will

be reviewed and rolled forward in 2011 in light of progress made. In 2012 the DHSSPSNI published an *Evaluation of Bamford Action Plan 2009-2011*, noting achievements and areas to be addressed in the next action plan. The evaluation states that whilst the objectives set in 2009 were not fully achieved, some progress has been made on many of the actions; namely early years, short breaks, family support pathways, CAMHS and Autistic Spectrum Disorder policy. Similarly, the RQIA *Independent Review of Child and Adolescent Mental Health Services (CAMHS) (2011)* highlights service improvements in response to the Bamford Review and made recommendation for further service developments. *Child and Adolescent Mental Health Services: A Service Model (DHSSPS 2012b)*, provides a framework for service delivery.

Further relevant policy documents include the *Learning Disability Service Framework (2012f)*, *Physical and Sensory Disability Strategy (2011-2015)* and *Autism Strategy (2013)*. The *Learning Disability Service Framework (2012f)* sets out standards for the planning and provision of health and social care services to people with learning disabilities and places an emphasis on taking service users' views into account in developing and monitoring standards. The *Physical and Sensory Disability Strategy (2011-2015)* focuses on the health and wellbeing of people with physical and sensory disabilities and their families and is relevant to both children and adults. It addresses issues relating to service provision, access to specialist equipment and supporting living as well as support for parents and carers. Finally, the *Autism Strategy (2013)*, developed in response to the requirements of the *Autism Act (2011)*, addresses definitions and prevalence and proposes a vision of inclusion for people with autism in cultural, social, political and economic life.

Chapter 8 reports on the review of the youth justice system in NI and subsequent implementation plan which highlights key areas for improvement including efforts to address the over-representation of looked after children and young people within the youth justice system and the mental health needs of children and young people within the youth justice service.

Chapter 9 focuses on education policy. The *Department of Education NI (DENI)* aims to ensure that the conditions for each child to fulfil their educational potential are available.

Some children need additional support and amongst these looked after children are identified as at particular risk of not meeting their educational potential. Four policy documents are considered in this section. The strategic policy document *Every School A Good School (DENI, 2009)* endorses an inclusive and child-centred approach in education, whilst also recognising the impact of a child's wider experiences in their familial and social environments on their engagement with and experience of education. *The Early Years Strategy (DENI, 2010)* highlights the importance of the early years as a foundational time for children when educational interventions can reduce the later impact of social or material disadvantage. These documents both refer to all children rather than being specifically focused on disabled children, however the latter are included in the broad policy described.

In 2012, DENI launched a consultation focused on Special Educational Needs (SEN). This UK wide document; *Support and Aspiration (2012)* was critical of current approaches that govern SEN and proposed a re-working of the system to enable improved longer-term outcomes for children and young people, which will challenge low aspirations for children with SEN and seek to ensure that every child fulfils their potential. In accordance with the duties laid out in the *Disability Discrimination Act (1995)*, DENI submitted a *Disability Action Plan (NI) 2012-2013* to the Equality Commission which details plans for the promotion of positive attitudes towards disabled people and their increased participation in public life through the critical arena of education.

Chapter 10 brings together the broad themes of the review indicating areas of commonality and difference across legislation and policy relevant to the lives of disabled children and young people who are looked after.

1. Introduction

In recent decades, there have been unprecedented developments in legislation and policy in Northern Ireland (NI) relating to disabled children and adults. Broadly speaking developments can be located in three key areas:

- Rights based legislation that either relates to all people, all children and/or all disabled people;
- Child care legislation and policy that relates to all children; and
- Disability and mental health legislation and policy that relates to all people with disabilities or mental health needs or people with specific types of disability or mental illness.

Importantly, disabled children, including those in care, are considered as a sub-group within these broader categories and there is no one overarching piece of legislation or policy that relates solely and specifically to all disabled children and/or disabled children in care. Despite this absence, there have been developments in legislation and policy which reflect the growing recognition of the complex, interwoven, and previously overlooked needs of this vulnerable group of children and young people and which impact on service expectations and responsibilities.

In the context of the present study the most recent definition of disability provided by the *UN Convention on the Rights of Persons with Disabilities* (United Nations, 2006: 4) is being drawn upon. This states 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.”* This means that law and policy relating to children and young people with mental health needs are included within this review, with a particular focus on looked after children with mental health needs. Throughout the report, the term learning disability is used instead of intellectual disability to reflect the terminology used in the local policy documents reviewed.

1.1 Structure of the Report

This report will first review the relevant international rights treaties designed to protect the rights of disabled children and young people, including relevant United Nations policy documents (UNCRC, 1989; UNCRPD, 2006) which detail minimum standards, goals and expectations of signatory governments. The review will move on to consideration of the local legislative landscape before reviewing Northern Irish policies relating to disabled children and young people who are looked after across child, disability and mental health policy areas. The review will then consider key trends identified in the review of law and policy.

2. International Human Rights Legislation

Human rights are firmly embedded in the underpinning principles of legislation and policy developments regarding children and disabled people. In the international context, three specific rights frameworks are of particular relevance: the *European Convention on Human Rights (1953)*; the *United Nations Convention on the Rights of the Child (UN, 1989)*; and the *United Nations Convention on the Rights of Persons with Disabilities (UN, 2006)*. **The European Convention on Human Rights (1953)** establishes fundamental human rights principles, which are applicable to both adults and children. Whilst the human rights detailed in general instruments are recognised as applicable to all individuals, those who are particularly vulnerable to discrimination are given specific consideration by the United Nations. Children, given their age and need of care and protection are one such group. **The United Nations Convention on the Rights of the Child (UNCRC) (1989)** details human rights and protections with specific reference to children. The rights of people with disabilities are also addressed in a bespoke human rights instrument. **The United Nations Convention on the Rights of Persons with Disabilities (2006)** is equally applicable to both adults and children and aims to address the rights of people with disabilities that not directly covered by other human rights instruments.

2.1 The European Convention on Human Rights (1953)

Within Europe the emergence of the rights agenda was a response to what were and are regarded as extreme violations of human rights, which took place during World War II, primarily the Holocaust. The Council of Europe, established in 1949, drafted the *European Convention on Human Rights (ECHR)*, as a founding European rights document which came into force in September 1953.

All articles of the ECHR are equally applicable to adults as to children so children are not a specific focus. The Convention provides broad statements of principle, which are open to wide ranging interpretation within the law. However, there are three articles that have

particular relevance to disabled, looked after children: Article 6, the right to a fair trial; Article 8, the right to respect for private and family life; and perhaps most pertinently Article 14, the right to freedom from discrimination. The Convention also established the *European Court of Human Rights*. Any person who believes their rights have been violated by the state can take their case to this court.

It is important to note that the Convention is a foundational document on which later rights treaties, focused on particular social groups, draw extensively. As noted in the introduction two such treaties drawn up by the United Nations are of particular interest to the present study namely the *United Nations Convention on the Rights of the Child* and the *United Nations Convention on the Rights of Persons with Disabilities* and these are each discussed below.

2.2 The United Nations Convention on the Rights of the Child (UNCRC) (1989)

The United Nations (UN) was founded in 1945 to promote international peace and security, develop better living standards and contribute to social progress globally. The UN considers and takes action on many issues particularly the development of human rights law.

While the UN is clear that human rights apply to all age groups, children have received special attention given their age, vulnerability and their need for care and protection. This view is supported internationally and has led to the emergence of the *United Nations Convention on the Rights of the Child* (UNCRC) adopted by the United Nations General Assembly in 1989.

The UNCRC views all children (including disabled children) as individuals entitled to a range of basic freedoms and rights exercised within the context of their families and their communities. It is underpinned by four basic principles:

- All children should be free from all forms of discrimination irrespective of the child's or his/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);

- In all plans and decision making affecting the child their best interests are a primary consideration (Article 3);
- All children have the right to life, survival and development (Article 6); and
- All children have the right to express their views and for those views to be taken seriously (Article 12).

All of the rights defined in the UNCRC are indivisible and interdependent. This means that they cannot be considered in isolation from each other and that the achievement of any particular right is dependent on the successful implementation of the others.

In Article 23, the UNCRC makes specific reference to disabled children recognising their right to provision of services, access to information and to education, health, employment and social and cultural activities, recognising the fact that disabled children should enjoy a *“full and decent life”* (Article 23:1,p.8).

Furthermore the UN periodically publishes General Comments that provide detailed advice and interpretation regarding the Articles contained in the UNCRC. In 2006 *General Comment No. 9 ‘The Rights of Children with Disabilities’* was published in recognition of the ongoing problems for this group of children. These are identified as *“exclusion from decision-making processes to severe discrimination and actual killing of children with disabilities”* (UN, 2009, p2, para 3) and barriers which include:

“not the disability itself but rather a combination of social, cultural, attitudinal and physical obstacles which children with disabilities encounter in their daily lives” (United Nations, 2006:2, para 5).

General Comment No. 9 highlights the need for a *“national action plan”* (p.5), in each member state, which integrates the provisions of the convention, is comprehensive, includes plans and strategies for children with disabilities and has measurable outcomes. It is also noted that states must ensure that disabled children are specifically and

intentionally included in generic policies and programmes.

General Comment No. 9 reinforces the need for the collation of data that is accurate, standardised, that allows for disaggregation and that reflects the actual situation for disabled children. In recognition of the ongoing problems regarding the delivery of services that are fragmented and delivered by a number of governmental and non-governmental organisations, the General Comment also stresses the need for the establishment of a co-ordination body for disabled children in each country. Strong emphasis is also placed on member states' obligations to support the carers of disabled children *“to enable carers to work, to relieve stress and to maintain healthy family environments”* (UN, 2009:11-12, para 41). In relation to disabled children in the care of institutions, specific attention is paid to their vulnerability and the measures required to combat their increased risk of abuse and neglect.

2.3 The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006)

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) which applies to all disabled people (children and adults) aims to address the gaps in human rights treaties that fail to directly address the rights of people with disabilities and:

“Promote, protect and ensure the full and equal enjoyment of all human rights by all persons with disabilities, and to promote respect for their inherent dignity”
(Harper et al., 2012: 2).

Article 1 of the UNCRPD provides the following definition of disability: *“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”* (p.3). This is significant in that it incorporates long-term mental impairment, stresses the impact of disabling barriers in society in interaction with an individual’s impairment and therefore, accepts the socially constructed and changing nature of disability.

Its underpinning principles, as outlined in Articles 3 and 5, include: respect for inherent dignity; individual autonomy; the freedom to make one's own choices; independence; non-discrimination; full and effective participation; inclusion; respect for difference; acceptance; equality of opportunity; accessibility; equality; respect for the evolving capacities of disabled children; and the preservation of their identity.

As outlined by Harper *et al.* (2012: 28-29), the UNCRPD prescribes the obligations the State is required to undertake under the broad themes of: protection and promotion; training personnel; providing services and assistance; consulting with disabled people (including children); developing awareness campaigns; modifying infrastructures; and involving disabled people in monitoring.

Specifically in relation to disabled children, Article 7 UNCRPD holds that *"State Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children"*(United Nations, 2011:7). Like the UNCRC, the best interests principle should apply and disabled children should:

"... 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" (United Nations, 2011:7).

The UNCRPD also adds that the situation can be improved for disabled children by early intervention programmes, training for staff, awareness raising campaigns and the development of a national strategy for the inclusion of disabled children (Harper *et al.*, 2012:65).

While the UNCRC and UNCRPD are mutually reinforcing, there are some differences in emphasis and wording. For example, although both mention a child's right to family life Article 23 of the UNCRPD requires State parties to ensure that disabled children have an equal right to family life [as all children] *"... to prevent concealment, abandonment,*

neglect and segregation of children with disabilities” (United Nations, 2011:13). Significantly, some of the language used here reflects the social stigma that was historically associated with having a disabled child. Moreover, the historical resonances continue with echoes of institutionalization, (still current in many parts of the world) informing the content of Article 23 UNCRPD as it goes on to state that:

“In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents” (United Nations, 2011:13).

That disability in itself should not be a reason for children to live apart from their families is a strong move away from received thinking of the past, and is an edifying support to the value of family life. It appears that, whilst The UNCRC and the UNCRPD are strongly in support of children ideally being brought up by their birth family, the latter places greater emphasis on protecting disabled children from barriers to experiencing family life on account of their disability. Further endorsing the importance of family life, though recognising birth families may not be able to provide on-going care for their disabled child; Article 23(5) notes that, state parties should ensure that *“every effort will be made to provide alternative care within the wider family, and failing that, within the community in a family setting.” (p.16)*

In relation to disabled children and their access to services, the UNCRPD highlights the rights of disabled children and young people to have access to education on an equal basis with others. Article (24) goes on to state that *“State Parties shall ensure an inclusive education system at all levels and lifelong learning”(p.16)*, including provision of *“reasonable accommodation of the individual’s requirements” (p.17)*, e.g. individualised support and the availability of a range of augmentative modes of communication, to enhance the education of disabled children. However, in ratifying the Convention the UK noted a reservation to Article 24 (among other reservations) in relation to the delivery of inclusive education. The UK government maintains a need to have both mainstream and special schools, whilst at the same time stating a commitment to increase access to mainstream schools so that they are equipped to meet the needs of disabled children.

Article 25 of the UNCPRD concerns health provision for disabled children and endorses the need for early identification of health needs, as well as appropriately timed intervention. Moreover, health services should be planned in such a way as to minimise and prevent further disabilities among children. Of particular relevance to children and with notable health benefits in relation to positive health or salutogenesis, is Article 30, which impresses on State parties the need to enable disabled children to access play and recreation activities and to take part in sports and leisure pursuits; these should include those provided in schools.

2.4 Impact of International Rights Legal Frameworks in Northern Ireland

The UNCRPD requires that States set up a framework, including one or more independent mechanisms to achieve the policy aims. The *Human Rights Commission* and the *Equality Commission* have been designated as the Independent Mechanism in NI responsible for the promotion, protection and monitoring of the implementation of the rights defined in the Convention. An indication of the successes of government and associated bodies/organisations in addressing the rights of disabled children can be found in the first periodic report on the implementation of the Convention to the *UN Committee on the Rights of Persons with Disabilities* (Office for Disability Issues, 2011).

Building on this, a recent report by Harper *et al.* (2012) from *Disability Action's Centre on Human Rights for People with Disabilities*, commissioned by the ECNI, identifies shortfalls in policy and programme delivery including: awareness raising; participation in public and political life; access to information and statistics and data collection (Harper *et al.*, 2012:5). The report considers each of the UNCRPD Articles in turn and, in relation to Article 7 Children with Disabilities, acknowledges the ongoing work of the *NI Commissioner for Children and Young People* (NICCY) and the OFMDFM funded *Participation Network* in relation to promoting the participation of disabled children and young people. In 2010 NICCY made recommendations for the development and implementation of a wide-ranging national strategy to effectively address the inclusion of disabled children within their communities and in society more generally; and, specifically, equality in education for disabled children. It was argued that whilst special schools can offer disabled children individualised and supportive educational

environments, segregation on the basis of disability may have a detrimental impact on children's opportunity to build social networks in their communities and may undermine opportunities to challenge negative stereotypes about disability as segregation and exclusionary practices are maintained. The Commissioner called for unnecessary physical and practical barriers to be challenged to enable more disabled children to be educated in mainstream schools and have access to the full range of learning opportunities they afford.

Harper *et al.*'s (2012) report notes that the *Participation Network* has advocated for accessible materials to be made available to young people with sensory impairments and learning disabilities so that they may be informed about Government consultations on matters that affect them. However, the report states that there are ongoing concerns about just how much direct consultation there is with disabled children and young people and their carers.

In relation to the role of the voluntary sector, the report (Harper *et al.*, 2012) highlighted the work of the *Children with Disabilities Strategic Alliance* (CDSA) and its manifesto aimed at promoting the rights and best interests of disabled children and young people, raising awareness of the daily exclusion they face and making recommendations for action to challenge barriers to inclusion.

A number of other voluntary agencies also have a remit to ensure that children's voices are heard. For example, *Cruse Youth Advisory Group*, *Young NCB NI*; *NICCY's Youth Panel*, *Young Voice* project, the *NI Youth Forum* and *Disabled Children and Young People's Participation Project*. A plan to enhance co-ordination between these groups is being developed to strengthen children's voices. While such initiatives are very encouraging, Harper *et al.* (2012) highlighted a range of shortcomings in relation to the way in which policies and programmes within NI are reaching the standards laid out in the Convention. They argue that equality and inclusion need to be brought about through systemic social change and multi-faceted action occurring at all levels of society.

Research, although at times fragmentary (Harper *et al.*, 2012), confirms some of the challenges that exist in the actualisation of disabled children's rights. The prevailing social and environmental climate creates a significant barrier with the high prevalence of childhood poverty experienced by disabled children and their families being reported in the research literature (Monteith *et al.*, 2009; Emerson *et al.*, 2010). Monteith *et al.* (2009) document the financial challenges faced by many families with disabled children in NI, almost one-third of whom they found to be living in poverty. The study also reported parental social isolation, stating that many participants had not been visited by a social worker, none of the children had received an assessment of their needs, nor had their parents received a carer's assessment. Few families had received short break services for their son or daughter. Educational support was also found to be wanting, with limited availability of classroom assistants, particularly as children progressed through their school years and lack of access to free school meals or uniform grants, even for those who were on an income falling below the poverty threshold.

Monteith *et al.* (2009) recommended that steps be taken to ensure that: carer's and children's assessments are carried out; support plans are instituted to assist parents with their daily caring duties; and more short break services are provided to support disabled children and their families. Further recommendations include enabling disabled children to have access to leisure and social activities, with particular relevance to low income families, with a view to enabling the growth of social inclusion and engagement outside of home and school environments. Other research confirms experiences of social isolation for disabled children and their parents, with disabled children having limited opportunity to establish friendships outside of their school and family environment compounded by restrictions to accessing leisure activities (Kilkelly *et al.*, 2004; Haydon, 2007; Dowling *et al.*, 2012).

These findings supported those reported by McMahon and Keenan (2008) which described the limited sustained support available to families with disabled children as well as ongoing evidence of bullying of disabled children (Mencap, 2007) and broader challenges for disabled children being routinely included and enabled to have full and equal access to their rights (Emerson *et al.*, 2007).

3. Rights-Based Legislation in Northern Ireland

Building on the international human rights legislation, a number of important rights-based documents feature in the Northern Irish legislative landscape.

The Human Rights Act (1998) enables individuals to have greater access to challenge rights violations outlined in the ECHR by enabling cases to be heard in UK courts.

The Northern Ireland Act (1998) established the ECNI whose role is to oversee discrimination and equality law. Central to protections for disabled people is Section 75 of the Northern Ireland Act, which imposes statutory obligations on public bodies to promote equality of opportunity between disabled and non-disabled people.

The Disability Discrimination Act (DDA) (1996) aims to eliminate discrimination on the basis of disability and promote equality of opportunity. The amendments to the DDA (1996) introduced with **The Disability Discrimination Order (Northern Ireland) (DDO) (2006)** broaden the definition of disability and require public bodies to promote positive attitudes towards disabled people and develop strategies to broaden the participation of disabled people in public life.

While these rights-based Northern Irish laws are not specific to disabled children per se, they do form overarching mechanisms through which equal access to rights by all people are enabled and supported.

3.1 The Human Rights Act (1998)

Under the provisions of the *Human Rights Act (1998)* individuals can claim the rights outlined in the *European Convention on Human Rights (ECHR)*. *The Human Rights Act (1998)* enables legal claims to be heard in courts within the UK rather than the European Court in Strasbourg. Thus, this Act increases the opportunity for individuals to challenge in court alleged breaches of their human rights. Moreover, the Act provides that local UK domestic legislation and the operation of public bodies is compatible with the rights outlined in the ECHR, and that incompatible legislation be abolished.

Article 8 of the *Human Rights Act* makes important guiding provisions regarding family life, noting the right to respect for private and family life, with the provision that there should be no interference by public authorities into this right unless (among other reasons) for the protection of health or morals or rights and freedoms of others.

3.2 Northern Ireland Act (1998)

The *Northern Ireland Act (1998)* provided for the establishment of the *Equality Commission*, which came into existence in October 1999. As an independent public body the role of the Commission is to oversee equality and discrimination law in NI. As such it brings together the duties and functions previously provided for under the auspices of the *Commission for Racial Equality*, the *Equal Opportunities Commission*, the *Fair Employment Commission* and the *Disability Council*.

Through promotion, advice and enforcement the ECNI aims to promote equality, encourage good relations and confront discrimination. In relation to disability, a key component of the *Northern Ireland Act (1998)* is Section 75 that requires public authorities to describe the processes through which they propose to meet their statutory obligations to promote equality of opportunity for disabled people, which are monitored by the ECNI and can be subject to enforcement. Complaints made against public bodies in relation to non-compliance with Section 75 can be addressed by the ECNI.

Concerns have been raised about the degree to which the provisions of the *Northern Ireland Act (1998)* have been enforced and there have been calls to bring forth legislation to amend Section 75 to make it “*justiciable and enforceable*” (Haydon, 2008:21). Further, a lack of direct involvement of children (Geraghty, 1999) and disabled children (Haydon, 2008) in matters that affect them has been highlighted. Reflecting this concern, in 2008 the ECNI produced guidance for public authorities on consulting and involving children and young people in the planning and provision of services, including a child-friendly version for younger children which may also be suitable for some young people with a learning disability.

3.3 The Disability Discrimination Act (DDA) (1995)

The rights frameworks of the *Northern Ireland Act (1998)* and *Human Rights Act (1998)* are generic in their focus (applying to all people). There is an additional national legal instrument that relates specifically to the rights of all disabled people namely the *Disability Discrimination Act (1995)*. This has the agenda of promoting and upholding the rights of disabled people, providing a framework for promoting equality and challenging discrimination on the grounds of disability. This Act defines disability as “*a physical or mental impairment that has substantial or long-term effect on a person’s ability to carry out normal day-to-day activities*” (p.8).

Discrimination is regarded to occur when an individual is negatively prejudiced without justification on account of their disability, or there has been a failure for a reasonable adjustment to be made to avert discrimination. The Act also requires public bodies and services to provide information to disabled people in respect of their rights.

A criticism of the DDA (1995) is that there is a lack of accessible information, which may leave individuals unaware of their rights, and therefore unable to avail of the potential benefits in terms of empowerment and knowledge of their right of access to services, to enjoy certain standards or seek redress under the Act. It is contended that those who may benefit most from its articles are those who are already strong self-advocates with keen awareness of issues of discrimination and inequality, whilst failing to adequately represent others (McConkey, 2006; Russell, 2003).

Geraghty (1999) has contended that the DDA (1995) does not adequately address matters of relevance or interest to disabled children, as it has a greater focus on adult centred issues. In a further criticism Harper *et al.* (2012) note a conflict between the medical model that underpins the DDA and the social model that underpins the UNCRPD and that until the State fully accepts the social model there will be challenges, “*regarding the interpretation and implementation of the Convention and its compatibility with existing legislative provisions under the DDA*” (Harper *et al.*, 2012: 15).

3.4 The Disability Discrimination (Northern Ireland) Order (DDO) (2006)

This Order provides for some amendments to the DDA (1996). Firstly, under the DDO (2006) the definition of disability includes people diagnosed with cancer, multiple sclerosis or HIV. There is also an expansion of the reach of the 1996 Act in relation to mental health which no longer needs to be “*clinically well recognised*” to be recognised as an impairment.

The DDO (2006) also requires public bodies to produce a scheme of action in relation to disability, which should be submitted to the Equality Commission. This should detail their plans for promoting positive attitudes towards disabled people and outline how they will encourage the participation of disabled people in public life.

4. Legislative Context for Disabled Children in Northern Ireland

Legislation relating to disabled children in NI is located across a range of disability and children's law. There is no one specific instrument focused on disabled children.

In relation to disability, the **Chronically Sick and Disabled Persons (NI) Act (1978)**, the **Disabled Persons (NI) Act (1989)** and the **Mental Health (NI) Order (1986)** have continued salience as they emphasise assessment of need and provision of services to meet identified needs rather than a one size fits all model of service provision. The **Carers and Direct Payments Act (2002)** extends this provision with the introduction of direct payments and carers' assessments. More recently, the **Autism Act (2011)** extends the DDA (1996) definition of disability enabling people with autism greater access to services and benefits and instructing government departments to develop a strategy and service plan for people with autism in NI.

The **Children (Northern Ireland) Order (1995)** is the primary statute regulating the care and protection of children in NI. It endorses the view that children are best cared for by their families however, provides guidelines and regulation for State intervention in the care of children where they are at risk of harm. A central principle of the Children Order is the concept of 'best interest' where the welfare of the child is at the core of decision making. The associated Guidance and Regulations and subsequent **Children (1995 Order) (Amendment) (Children's Services Planning) Order (NI) 1998** address statutory planning processes and requirements in relation to, looked after children and disabled children. **The Children's Homes Regulations NI (2005)** guide process and practice in relation to the welfare of children and the management of children's homes. **The Children (Leaving Care) Act (NI) (2002)**, **Children (Leaving Care) Regulations (NI) (2005)** and **Leaving and Aftercare: Volume Eight Guidance and Regulations (DHSSPSNI, 2005)** provide detailed guidelines and regulation in relation to young people who are leaving care.

This section will begin with an analysis of the disability-related legislation concerning disabled children and young people. This will be followed by a review the children's legislation pertaining to disabled children and young people, including a focus on those who are looked after in NI.

4.1 The Chronically Sick and Disabled Persons Act (NI) (1978) and the Disabled Person Act (NI) (1989)

The Chronically Sick and Disabled Persons Act (NI) (1978), and the *Disabled Persons Act (NI) (1989)* continue to inform current thinking relating to the provision of services for disabled children and young people in NI. Of relevance to disabled looked after children are specific provisions such as the duty to assess the needs of disabled people, as well as a requirement that information should be made available by right, and that a representative can be appointed to advocate for disabled people.

Apart from specific provisions, the ongoing impact of this legislation is to be found in underpinning principles of a quality of life approach and the provision of services based on assessed need, a strong precursor to the current personalisation agenda present in many current policy documents, some of which will be reviewed below.

4.2 Mental Health (NI) Order (1986)

The main mental health statute is the *Mental Health (NI) Order (1986)* which addresses the assessment, treatment and rights of people with mental health needs. The Order also provides for compulsory community-based guardianship and hospital detention for those experiencing a mental disorder. Rights are also afforded to the nearest relative who may make an application for compulsory hospital admission and be consulted about the person's treatment and discharge. Although the Order is applicable to all people, there is no special provision for those under 18 apart from paragraph 33 which acknowledges children and young people in care and authorises that their guardian shall be the HSCB/HSCT whose care they are in, or in the case of young people under a residence order, the person named in the Order. This legislation is widely considered to be outdated with an over-emphasis on hospital care and limited guidance on how health and welfare decisions should be made for people who lack capacity (Bamford Review, 2007). Currently, the NI Executive and DHSSPSNI are developing new legislation known as the Mental Capacity Bill which will combine mental capacity law and mental health law into a single framework and provide one piece of legislation to deal with all health care decisions including welfare and finances. In keeping with current UK legislation, it is proposed that the legislation will apply to people aged 16 and over; however there has

been much debate over this threshold as children reach maturity at different stages and may or may not have the same capacity to make decisions as an adult. The Children's Law Centre (2009) has emphasised the need for advocacy for young people to ensure their right to have their views and wishes taken into account by those making decisions about treatment or intervention.

4.3 Carers and Direct Payments Act (NI) (2002)

This Act introduced the statutory right to an assessment of carers' needs, the provision of services to assist carers and to make provision for direct payments to individuals in lieu of personal social services. Carers include people who have parental responsibility for disabled children; however, disabled children who are over 16 years of age can be assessed for direct payments to meet their own needs.

This Act makes provision for an amendment to the *Children (NI) Order (1995)* (discussed below) as Article 18b states that the Department may make provision for the issue of vouchers to the person with responsibility for the disabled child. Vouchers can be used to purchase services to support the child's needs.

Direct payments may offer greater choice and control to parents and children in relation to the services they can access. There is a growing uptake of direct payments, however one obstacle is thought to be the bureaucracy involved in managing direct payments, which are reported by some to be complicated and burdensome.

4.4 The Welfare Reform Bill for Northern Ireland

The Welfare Reform Bill is still subject to the approval of the Northern Ireland Assembly, and is currently undergoing 'further consideration' by the relevant committees. The Bill heralds significant changes to the welfare benefits system in NI (mirroring changes more widely in the UK) in how entitlement is judged, how benefits are designed and administered. Whilst there are no specific mentions of looked after children, there are a number of implications within the Bill, as it currently stands, which are likely to impact on disabled children and young people.

For young people aged between 16-18 (as well as adults) it is proposed that the Disability Living Allowance (DLA) will be replaced with a new benefit called Personal Independence Payment (PIP). Reassessment for entitlement to PIP for those who have been in receipt of DLA will take place with a health care professional and will involve assessment in relation to two components the Daily Living Component and the Mobility Component. The Northern Ireland Welfare Reform Group (2012) have put forward a number of concerns regarding these proposals; namely, the potential for distress being caused to individuals in relation to the face-to-face assessment of eligibility; the fact that the life-time or indefinite awards available under DLA will cease even for those who have progressive conditions, being replaced with 5-10 year awards with review periods; the right to mobility vehicles will be removed should the person in receipt of benefit spend 28 days or more as a hospital inpatient in any 365 day period. For young people, families may depend on a mobility vehicle and this caveat to its provision fails to recognise the complex health care needs experienced by some disabled children and young people. Further implications relate to carers' allowances which are linked to the receipt of PIP, the former can be claimed only when the latter is in place. The threat of additional financial strain for families who may already be facing considerable pressures is likely to arise.

Just as PIP will replace DLA, a new single benefit, namely, Universal Credit will replace a range of current benefits. This will affect adults and also some young people aged 16-18 who are eligible to claim. Children with disabilities will also be affected by Universal Credit. The new benefit will include a 'disability addition' as well as a 'higher addition' for disabled children. The higher addition will be similar to the amount available to children who are currently in receipt of the higher rate DLA, however those currently receiving the lower rate DLA will receive the new disability addition which will be half of the current benefit in cash terms. NICCY reported that this benefit cap could impact on families where there is a severely disabled child and may impact on the lives of 6,500 children in NI (Horgan and Monteith, 2012). Additional pressure on families will result from the limited availability of child care for disabled children and the costs associated with accessing care (NI Welfare Reform Group, 2012).

In the budget statement which introduced changes to welfare provision, the Chancellor of the Exchequer, George Osborne states that reforms would ensure that the most vulnerable are protected. However, concerns raised in relation to current welfare reform highlight new pressures which may impact on families caring for a disabled child, who may already be experiencing financial difficulties and challenges associated with the role of carer.

4.5 The Autism Act (2011)

This Act constitutes an amendment to the definition of disability in the *Disability Discrimination Act (1995)* to include social and communication impairment and functional ability. This brings entitlements for people with autism into line with the rest of the disability sector and sets in place processes for monitoring and accountability of services. It provides a duty to develop an Autism Strategy (see review of this strategy in section 7.6) within two years of the passing of the Act and, as such, instructs government departments to cooperate in the planning and implementation of an agreed strategy and service plan for individuals with autism. Further, the Act places a duty on government departments to agree a common system of data collection to enable accurate estimates of prevalence so as to inform effective future service planning for people with autism. There is also a clear directive for family support provision, which places a duty on the DHSSPSNI to detail how the needs of families and carers will be addressed.

4.6 Children (NI) Order (1995)

The *Children (NI) Order (1995)* is the foremost statute regulating the care and protection of Northern Irish children. Its underpinning principles, often known as the five 'p's, are: paramountcy; parental responsibility; prevention; partnership; and protection. The legislation accepts, in line with the UNCRC and UNCRPD, that children are best cared for where possible in their own families. Reflecting this fundamental principle the Children (NI) Order (1995) requires Health and Social Care Trusts (HSCTs) to support families to prevent children's entry into care. In relation to disabled children this includes the provision of short breaks to enable families to continue to care for their disabled child at home for the majority of the time.

The welfare of the child is considered to be paramount and where children are at risk of harm, neglect or abuse; or where parents are not able to continue caring for them, children should be removed from the family home; though this should be a last resort when other options have been exhausted. The legislation makes it clear that birth parents retain parental responsibility for their children in state care. Freeing for adoption and the making of an adoption order are the only legal mechanisms through which birth parent legal responsibility can be severed. Trusts are, therefore, under a legal duty to make every effort to work in partnership with parents informing and involving them in all decisions made in relation to their child. This principle extends to relationships with other professionals, the extended family and the child themselves where Trusts have a legal responsibility to support their participation and involvement in decision making.

Particular guidance is given in relation to the participation of children with complex needs or communication difficulties. It is noted that:

“Even children with severe learning disabilities or very limited expressive language can communicate preferences if they are asked in the right way by people who understand their needs and have the relevant skills to listen to them.” (DHSSPSNI, 1995: 26).

The Guidance cautions against tokenism and calls for the real participation of disabled children using a range of strategies to ensure they are successfully included in matters affecting them.

Looked After Children under the Children (NI) Order (1995)

Within the *Children (NI) Order (1995)* a looked after child is defined as a child who is accommodated by a Trust for a period of 24 hours or more. A child may be accommodated with foster carers or in a children’s home, or they may be placed by the Trust with extended family (known as kinship care). Children may be accommodated on an ongoing basis or for a prescribed period as a short break. Policy across the UK differs in relation to short breaks. For example in England children in short breaks for more than

24 hours may not be categorised as looked after if the placement is for the purpose of family support.

A child can become looked after following a voluntary agreement between the Trust and the child's parents (or others who have parental responsibility) or as the outcome of a legal order granted to the Trust by a court, usually when the child has suffered or is likely to suffer significant harm.

There is a statutory duty on HSCTs to regularly undertake a case review of looked after children and to produce and review care plans made in respect of each individual child (Articles 45 (1) and (2)). The initial review must take place within two weeks of the child's entry into care, and be followed up within three months. Subsequently, six monthly reviews are required. In relation to the health of looked after children, regulations under the Children (NI) Order (1995) require that care plans include arrangements for meeting the child's health needs and an annual health examination (6 monthly for <5's).

The Trust also has a duty to promote continued contact between children and their birth families and other significant relatives, so far as this is practicable and with due cognisance of the child's welfare (Article 29). The Trust may also assist with the financial costs for families to visit their child where there is economic need (Article 30). There are a number of additional articles that govern access arrangements, for example Article 53 (1-3) that defines the degree of access, and Article 53 (4-6) where the Trust can apply to the court to be allowed to refuse contact due to concerns about the child's welfare.

Disabled Children under the Children (NI) Order (1995)

Reflecting a medical model perspective, the *Children (NI) Order (1995)* defines a disabled child as: "*blind, deaf or dumb suffering from mental disorder of any kind or substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed*" (Article 2:2). The DHSSPSNI recognises that these words may be stigmatising (DHSSPSNI, 1995:11).

Under Article 17, disabled children are identified as a specific group defined as “*children in need*” thus establishing their access to family support services. Under Article 18A, Trusts have a mandatory and statutory responsibility to carry out assessments of carers of a disabled child and include outcomes of such assessments in decisions regarding service provision. Article 27(9) relates specifically to disabled children in that, where the Trust is providing accommodation for a disabled child, it must ensure that the accommodation is suitable to the child’s needs.

Furthermore Schedule 2 (para.3) provides for Trusts to open and maintain a register of disabled children; and under Schedule 2 (para.7) Trusts are required to provide services that minimise the impact of the disability and that provide opportunity for disabled children to reach their full potential.

Detailed guidance on the implementation of the Order can be found in the eight volumes of Regulation and Guidance that accompany the *Children (NI) Order (1995)*. Volume 5 specifically addresses ‘*Children with a Disability*’ (DHSSPSNI, 1995). The guidance is underpinned by the principles of inclusion and collaboration across social services, health and education. The participation of disabled children and their parents in assessment and decisions about service provision is also emphasised.

With regard to short breaks for disabled children the guidance states that no single placement should be longer than four consecutive weeks and, annually, a child should not spend more than 90 days in a short break placement. In respect of hospital care, children should not be accommodated in hospitals without the need for specific medical care. However, the relevant Trust should be notified of children who have been accommodated in a hospital for a period exceeding three months. This provision also applies to nursing homes and residential schools.

4.7 The Children (1995 Order) (Amendment) (Children’s Services Planning) Order (NI) (1998)

This piece of legislation amended the *Children (NI) Order (1995)* to make it a statutory duty to: review services on an annual basis; publish plans in relation to that review; and,

in carrying out the review, consult with other professionals from organisations including Health and Social Care Trusts, Education and Library Boards; Housing Executive; Probation Board; Chief Constable and relevant voluntary organisations.

4.8 The Children's Homes Regulations (NI) (2005)

The Children's Home Regulations (NI) (2005) came into operation on the 1st April 2005. They guide process and practice in respect of all aspects of children's homes, broadly covering the welfare of children, staffing, records, premises and management. The needs of disabled children are recognised in relation to equality of provision for the welfare of all children with due regard for the needs of disabled children (among others). For instance, there is a requirement that access to aids, equipment and support should be provided to facilitate communication needs (Part III, 15 [5]), and that failing to provide such aids will be a disciplinary matter (Part III, 16 [3j]).

Addressing health needs, the regulations again endorse the responsibility that disabled children (and all children) are provided with the aids and equipment arising from particular health needs (Part III, 19 [1c]). There are requirements that homes are at all times staffed by suitably qualified, competent and experienced persons, in respect of the demands of the environment, including the number and needs of the children accommodated and any needs arising from disability. The regulations note that if the home is intended to accommodate children who are disabled or who have special needs that this should be included in the statement of purpose.

4.9 Children (Leaving Care) Act (NI) (2002), Children (Leaving Care) Regulations (NI) (2005) and Standards for Leaving Care Services in NI (DHSSPSNI, 2012b)

The Children (Leaving Care) Act (NI) (2002) amends the *Children (NI) Order (1995)* to place duties on HSCTs to prevent premature discharges from care and improve assessment, planning and support for care leavers. The Act makes new provisions for HSCTs to maintain contact with young people leaving care and ensure their welfare even after they leave care. Their duty extends until the child is 21 years or later if the Trust is supporting further education and training. HSCTs should appoint a Personal Advisor and develop a pathway plan to promote independence which should be routinely reviewed. Finally,

HSCTs are expected to assist and support the ongoing education and training of care leavers, including education and accommodation expenses until the age of 24.

The *Children (Leaving Care) Regulations (NI) (2005)* support the provisions of the Act and provide more detailed guidance for HSCTs on how best to assess and meet the needs of care leavers. The regulations include: the qualifying criteria for leaving and aftercare arrangements; the assessment of need preparation and review of pathway plans to improve support for care leavers; the functions of personal advisors to ensure better support for young people after they leave care; and finally the assistance available for care leavers with regards to education, training, financial support and accommodation.

A care leaver is defined as a person who has been looked after for at least 13 weeks, since the age of 14, and who is in care on their 16th birthday. The status of care leavers is further divided into eligible, relevant, former relevant and qualifying young people. An eligible young person is aged 16-17 and has been looked after for at least 13 weeks since the age of 14 and is currently looked after. A relevant young person must be aged 16 or 17, be eligible and have left care. Former relevant young people are aged 18-21 (or older if they are in further or higher education or training) and, before turning 18, were either eligible and/or relevant young people. The specific additional support required by care leavers with disabilities or mental health needs are not addressed however the regulations do acknowledge that accommodation for care leavers, where reasonably practical, should be suitable for those with any form of disability.

Volume Eight of the Guidance and Regulations for the amended Children (NI) Order 1995 on leaving and after care services (DHSSPSNI, 2005), however, has a section solely focused on the additional needs of disabled young people leaving care. This guidance highlights the importance of: suitable training, employment or meaningful day opportunities; addressing sexual health education needs; building self-esteem; increasing ability to make decisions and assume adult responsibilities; and working closely with other service sectors to support transition to adult life. The guidance also recommends particular attention should be given to disabled young people who do not meet the criteria to access adult health and social care services.

In 2012, the DHSSPSNI published *Standards for Leaving Care Services* which specify the services and procedures that should be established to ensure quality services for care leavers, including corporate parenting responsibilities (DHSSPSNI, 2012e). The standards highlight the importance of person-centred care planning, ensuring the health and wellbeing of young people as they leave care and encouraging care leavers to reach their full potential. Attention is also paid to the importance of appropriate and safe accommodation as well as the promotion of engagement in further education, employment and in local communities. Finally, the Trusts' duty of care to young people leaving care leavers is emphasised, including their role in relation to advocating and supporting them in their transition to adult life. Only two of the Standards specifically mention the additional needs of those with mental health needs and/or disabilities in relation to preparation, planning and review, and addressing additional health needs.

5. The Strategic Policy Context for Disabled Children in Northern Ireland

This section reviews four documents that provide strategic direction to contemporary policy relating to disabled childhood in NI. It includes the: **Our Children, Our Young People, Our Pledge (2006)** 10-year strategy aimed at improving outcomes for children and young people in NI; **Transforming Your Care (2011)** review of health and social care in NI; **Strategy to Improve the Lives of Disabled People (2012)**; and **Child Poverty Strategy (2011)** which presents a strategic framework for eradicating child poverty in NI by 2020.

5.1 Our Children and Young People – Our Pledge (OFMDFM, 2006)

In 2006 the Office of the First Minister and Deputy First Minister (OFMDFM) published a 10-year strategy which sets out high-level outcomes for all children and young people and continues to act as a key reference point for children's policy; for example, *Care Matters* (DHSSPSNI, 2007) and *Families Matter* (DHSSPSNI, 2009) discussed below. The overall aim of this strategy is to improve outcomes for children and young people across a range of health, educational, social and environmental indicators. It recognises the interconnectedness and impact of factors such as poverty, health, and education.

There is an acknowledgement that insufficient progress has been made for the most disadvantaged and marginalised children. In response, this document emphasises family support and quality universal services alongside targeted interventions for those in particular need. Notable amongst these are looked after children and disabled children. The longitudinal nature of the strategy is highlighted, the impact of which should be measured against six core outcomes over time. These are that children and young people in NI are:

- Healthy;
- Enjoying, learning and achieving;
- Living in safety and with stability;

- Experiencing economic and environmental wellbeing;
- Contributing positively to community and society; and
- Living in a society which respects their rights.

These outcomes are rights-based and recognised as inter-dependent; that is that deficits in one area are likely to impact on another. Looked after children and young people are identified as a vulnerable group with targeted goals in relation to achieving stability of placement and permanence, reducing the potential of social exclusion, improving educational outcomes and enabling enhanced outcomes in relation to employment, health and wellbeing.

A range of measures are recommended including support for foster carers and residential staff to promote improved educational outcomes and provision to remain living with foster carers beyond the age of 21. Although not specifically mentioned, this may have particular relevance for disabled looked after young people in relation to the potential for them to achieve a sense of stability and permanence in a foster placement as they transition into young adult life.

Furthermore, two further drivers to change for looked after children and young people are noted: firstly, that they should be encouraged to remain in education or training until the age of 21; and secondly, that they should be empowered to actively engage with the care process with the aim of getting the best outcome from their situation. The latter aim is further underlined by an encouragement for a peer mentoring and independent advocacy service to empower children and young people who are looked after to voice their views.

Disabled children, including those with mental health difficulties, are not mentioned specifically in relation to being looked after. Drivers to change in relation to children with learning disabilities and mental health difficulties are reported to be primarily informed by the Bamford Review. The convergence of circumstances, which might lead to additional vulnerability (being a disabled child and looked after), is not specifically addressed in this ten year strategy, although there is an awareness of the general need to

deliver improved outcomes for those experiencing “*multi-faceted need*” (OFMDFM, 2006:82).

5.2 Transforming Your Care (DHSSPSNI, 2011)

This review of health and social care in NI was launched by the DHSSPSNI in December 2011. In response to changing philosophical, social and demographic trends, *Transforming Your Care* presents a new vision for the future of health and social care. Of the eleven drivers to change, many of which are general or applicable to the wider population, there are two which are most relevant to disabled, looked after children: patient-centred care (reflecting the personalisation agenda); and “*giving children the best start in life*” (DHSSPSNI, 2011:48).

Four main themes underpin proposed changes to the provision and delivery of health and social care: person-centred care which is individual, personal and responsive to need; evidence-based services reflecting knowledge of the changing Northern Irish population; effective safeguarding for those who are vulnerable in our society; and fit for purpose services which are innovative, multi-agency, sustainable and value for money.

Section 12 of *Transforming Your Care* focuses attention on family and child care. In relation to looked after children this section notes the overarching principle of the *Children (NI) Order (1995)* that children do best when cared for by their birth family remains a guiding standard. However, the review goes on to report on an increase in the numbers of looked after children in NI in the five years from 2005-2010.

Section 12, with a focus on family and childcare, states that the: “*needs of disabled children remain a priority for commissioners and providers alike*” (DHSSPSNI, 2011: 85). However, it proceeds, without specific reference to disabled children, to highlight the principles that underpin child and family services including: early intervention; multi-agency working to address the complex needs of children and families; partnership working; family centred care to address child and parent support needs; and kinship care. However, the review points out that there is significant under-investment in children’s services in NI, which may stifle the potential for such service development.

Frustration at the pace of implementation of the recommendations of the Bamford Review (discussed below) is acknowledged however there is no commentary on the barriers to its implementation. Sections 13 and 14 of *Transforming Your Care* focuses on people who use mental health services and learning disability services respectively. However, the main thrust of these sections relates to the adult population and does not specifically discuss children with mental health difficulties or learning disabilities.

Transforming Your Care (2011) does, however, make three recommendations of particular relevance to the disabled, looked after children and young people. These include: the promotion of foster care both within families in the form of kinship care and more generally; the development of a professional foster care scheme for the hardest to place children which is likely to include disabled children (Baker, 2007); and the development of a *Head Start Scheme* for 0-5 year olds in which disabled children should be integrated. This could be a significant support structure for parents of disabled children who are often reported to be more socially isolated than other parents (Collins *et al.*, 2013).

5.3 Improving Children's Life Chances - The Child Poverty Strategy (NIE, 2011)

The Child Poverty Strategy (2011) is a response to the requirements of the *Child Poverty Act 2010*, establishing a cross-departmental strategic framework to eradicate child poverty in NI by 2020. The strategy highlights the inter-connected impact of social, health, environmental and educational matters on the production and perpetuation of poverty. Four strategic priorities are identified: ensuring that poverty and disadvantage in childhood does not influence outcomes in adult life; supporting parents to be in work which is financially beneficial; ensuring children live in an environment which enables them to thrive; and providing financial support that is targeted and responsive.

These strategies are build on a number of principles, some of which resonate with other current documents reviewed here, for instance adopting a family centred approach, early intervention, partnership working between related agencies, placing the child at the centre of strategy and taking their views and perspectives into account. In addition,

tackling the root causes of poverty and breaking the cycle of intergenerational poverty are highlighted.

The strategy identifies groups at greater risk of poverty including families where one adult member is disabled. However, this reference to disability is more attuned to one parent being disabled, than to those families where there is a disabled child. Whilst it is widely recognised in the research literature that disabled children are at greater risk than non-disabled children of living in long-term poverty (Blackburn *et al.*, 2010; Emerson, 2010; Monteith *et al.*, 2009), this risk is not highlighted in the strategy. Although the document is not specifically attentive to issues affecting looked after children and young people, it does note that care leavers are particularly vulnerable to poverty and educational outcomes for this population are significantly poorer in comparison to those who have not been looked after.

5.4 A Strategy to Improve the Lives of Disabled People – 2012-2015 (OFMDFM, 2012)

In March 2012, the OFMDFM published this disability strategy with the express purpose of addressing its commitment to fulfil the requirements of the UNCRPD and setting out a high level policy framework to guide government departments on disability policy issues. This strategy has been shaped by the recommendations of the report issued by the Promoting Social Inclusion (PSI) working group (OFMDFM, 2009) which identified barriers to social inclusion and actions required to tackle these. The vision outlined in this strategy is for:

“a future where disabled people contribute to and benefit from the cultural, social, political and economic life of Northern Ireland on an equal basis with others.”
(OFMDFM, 2012:4)

Amongst a list of seven specified goals, early years and family support are highlighted. It is recognised that restrictions in choice of child care options, additional costs of raising a disabled child, inadequate provision of information as well as a lack of service co-ordination all lead to increased challenges and greater social isolation of families with disabled children. The remaining goals are relevant to disabled people of all ages, such as

choice and control, information and communication and bringing about change. Indeed, the strategy is intended to be inter-generational in reach and to include all impairment types.

Three of the sixteen strategic priorities identified make specific reference to children and young people. Firstly, Strategic Priority 7 is focused on increasing the level of choice, control and freedom that disabled people generally have in their daily lives. With specific reference to children this Strategic Priority recognises the challenges to choice, freedom and control imposed by the increased vulnerability of disabled children to abuse or neglect; stating that these children are more likely to be abused than their non-disabled peers, with an increase in risk in relation to the presence of multiple disabilities.

Secondly, Strategic Priority 8 pays particular attention to families with disabled children with emphasis on ensuring that they have access to the support they require in enabling disabled children to fulfil their full potential. Quoting Article 23 of the UNCPRD, which is directly concerned with respect for home and family life, this priority also recognises the role of State parties in providing alternative care for disabled children where their birth family is unable to care for them. This brief specific reference to disabled looked after children, is the only one contained in this document.

Thirdly, Strategic Priority 9 is attentive to the needs of disabled children as they make the transition to adult life and recognises barriers faced in finding appropriate support at this important life transition. This priority calls for equality so that disabled young people are afforded the same opportunities during post-school transition as their non-disabled peers. There is no reference to transitions to adult services for looked after young people. Other themes present in the Strategy are relevant to the social and environmental experiences of disabled children, which may further contribute to their exclusion. Firstly, families with a disabled child have an increased likelihood of risk of poverty or social exclusion linked to the increased costs of raising a disabled child and possible loss of income as parents may have to leave the labour market to provide for the child's care needs (Blackburn *et al.*, 2010 in Read *et al.*, 2012). Whatever the cause or outcome, many

disabled children live in poverty with Monteith *et al.* (2009) reporting that almost 1:3 disabled children in NI live in poverty.

6. Key Child and Family Policy

Whilst there is a range of child and family policy in NI, there are none with a sole focus on looked after children. This group are either referred to directly within wider policies or they are included by inference in policy for all children and young people. Six documents are reviewed below.

Care at its Best (DHSSPSNI, 2005) reports on a multi-disciplinary regional inspection of hospital services for disabled children in NI. This report provides a profile of disabled children and young people staying in hospital for three or more months and reasons for hospital admission. The report expresses concern about children and young people with learning disabilities being accommodated in adult hospital wards and disabled children being placed in hospital settings for respite purposes. **Care Matters** (DHSSPSNI, 2007) is a strategic document setting out a framework for the delivery and development of child and family services. The following year **Understanding the Needs of Children in Northern Ireland (UNOCINI)** (2008) was introduced to ensure a single assessment framework for identifying children's needs. It too is underpinned by the whole child approach and includes specific guidance in relation to assessing need across a range of pathways. **Families Matter** (DHSSPSNI, 2009) focused on a whole child, family-centred approach and is attentive to the prevention of family breakdown, identifying the family as the best environment in which to raise children, if it is in their best interests.

The **Healthy Child, Healthy Future** (DHSSPSNI, 2010) strategy outlines a health promotion programme targeted at all children including looked after and disabled children. It places considerable emphasis on the role of parents and families in the promotion of good health and the prevention of illness. The **Children and Young People's Strategic Plan 2011-2014**, provides an integrated, cross-sectoral approach to children's services planning and development. It adopts a rights framework and strongly advocates that the views of children and young people are included in planning and decision-making processes. Both of these documents emphasise early intervention, prevention and joined up services. Finally, the **RQIA reports on Community Services for Children with a Disability** and **Safeguarding Children and Vulnerable Adults in Hospitals** (2013) outline the findings of a review of community services and an inspection of safeguarding practice for those residing in mental health and learning disability hospitals. These reports highlight good practice and areas where improvements are required.

6.1 Care at its Best (DHSSPSNI, 2005)

The DHSSPSNI launched the 'Care at its Best' report of a multi-disciplinary regional inspection of hospital services for disabled children in NI, led by the Social Services Inspectorate in 2005. The inspection was initiated following concerns raised by the Children Matter Taskforce about the number of disabled children spending lengthy periods of time in hospital due to the lack of appropriate community provision. The inspection focused on children and young people who had stayed in hospital for three months or more. Of the 173 children and young people with hospital stays of three or more months, the inspection found that slightly more boys than girls and significantly more Catholic than Protestant children (DHSSPS NI, 2005:6). The main reasons for hospital admission were challenging behaviour, in hospital since birth and risk to self (DHSSPSNI, 2005:7). Despite the Government aim that by 2002 children should not be admitted to specialist hospitals, other than in exceptional circumstances (DHSSPSNI, 1997; DHSSPSNI, 1998), the inspection found 31 children and young people had been accommodated in the adult wards of a range of hospitals in NI, mostly children and young people with learning disabilities. Although no children should be admitted to hospital for reasons other than clinical needs, the inspection found that some hospitals retained beds for respite purposes for children. In particular, two residential respite care units associated with hospitals were operating outside the regulations of the Children (NI) Order 1995 and some children had remained in these units for a number of years. Following this report, progress towards ending hospital admission for disabled children for reasons other than clinical needs was slow. Indeed, in 2007, the Health Minister was prompted to announce a £3million action plan to ensure no children with learning disabilities remained in hospital by 2009. Following on from this policy aim, the first annual review of the Northern Ireland Children's Services Plan in 2008-2009 (HSCB, 2009a) reported that all children in Muckamore Abbey Hospital have been resettled in new homes in the community.

6.2 Care Matters in Northern Ireland: A Bridge to a Better Future (DHSSPSNI, 2007)

Following the UK Green Paper *Care Matters* (DFES, 2006) and the 10-year children's strategy, *Care Matters* set out a framework for the delivery and development of child and family services. *Care Matters* describes the family as the "bedrock of society" (p.1) and

states that the most effective and preferable way to bring up children is within a family context and emphasises support to prevent family breakdown.

However, for those who cannot remain with their birth family this policy document underlines the need for stability and permanence in the lives of children and young people. To this end, steps should be taken to place children with extended family in a kinship care arrangement, or through adoption or long-term fostering. It is noted that children with 'special needs' are more likely to be fostered or adopted if *"appropriate support and infrastructure was in place to support their long term needs."* (p.19).

Ongoing concerns regarding poor outcomes for looked after children are highlighted in relation to social and educational indicators, as well as longer-term outcomes into adult life. A vision for this group of children is set out, in which the role of the State as the corporate parent is emphasised. Staff acting in the role of corporate parent should do what every good parent does in offering children good quality care, hope and ambition. For looked after children there is an added emphasis on promoting stability and permanence and on ensuring that their views and perspectives as well as those of their families are considered.

The policy is strongly founded on a rights-based perspective and this is apparent in relation to disabled children where it is reported that due attention is given to the mainstreaming of services for those with a physical, sensory or learning disability. The policy is also attentive to the health care needs of disabled children, which may be causal to, or consequent of, the child's impairment. The policy recommends the creation of the role of lead health care professional to ensure that the health care needs of all looked after children, including disabled looked after children, are attended to.

Care Matters highlights the high percentage, estimated at almost one third of the looked after child population, who experience mental health difficulties and require the support of CAMHS (p.20). However, it is reported that the level of provision of specialist intensive support and CAMHS is insufficient to meet these needs. The development of dedicated CAMHS for children in care, based on a multi-systemic therapy model, is recommended.

This echoes calls made in the Bamford Review (reviewed below) for a regional service model that prioritises and meets the needs of looked after children with disability and/or mental health needs.

6.3 Understanding the Needs of Children in Northern Ireland (UNOCINI) (DHSSPSNI, 2008)

Following a central recommendation of the *'Care at its Best'* inspection report (DHSSPSNI, 2005), the *UNOCINI guidance* (DHSSPSNI, 2008) provides a single assessment framework for identifying children's needs. It is underpinned by a whole child, systemic approach based on Bronfenbrenner's (1994) social ecological model of development and bringing together the child's needs across a range of domains including physical, health, care, education, family life, social, cultural and spiritual needs.

Within the UNOCINI guidance, disabled children and looked after children are identified as children in need (level 3) or children with complex or acute needs (level 4). At level 3, the HSCT is required to provide community based social care services to support parents caring for a disabled child and to promote and safeguard the welfare of children, including short break services. Assessment includes consideration of the need or otherwise for a Statement of Educational Need. Children in need may also, due to family circumstances, be added to the child protection register, and a multi-disciplinary child protection plan established. At level 4, children are experiencing, "*acute, intense or complex difficulties because of health, disability or vulnerability due to their family situations*" and should have access to services targeted at meeting their particular needs (DHSSPSNI, 2008: 9).

The particular care and support needs of disabled children are given specific attention in the UNOCINI guidance across a number of areas noted below:

- With regard to children and young people's participation in assessment processes, the guidance clearly states that practitioners should avoid the assumption that disabled children, including those with a learning disability are, "*not capable of understanding*" (DHSSPSNI 2008: 28).

- Practitioners are encouraged to be aware of the potential impact of impairment or disability on the child's social and emotional development, including risk of low self-image and poor self-esteem known to be associated with disability and often linked to bullying or discrimination.
- Reflecting a social model perspective, disabling social circumstances and environment are recognised as barriers to services and community participation, which may increase the impact of impairment.
- To avoid failure to recognise needs beyond those relating to the child's impairment, the guidance recommends that (a) the child's welfare needs are recognised and clearly defined; (b) there is a high degree of collaboration between all professionals and agencies to enable rigorous planning and assessment and strong communication strategies and; (c) a holistic approach is adopted to ensure that all the child's care and support needs are identified and addressed.

Whilst the UNOCINI guidance provides a specific focus on disabled children, the threshold of need and threshold of intervention documents that accompany it pay less attention to their particular needs. This may limit the impact of the guidance on practice and may underplay consideration of the complex and multi-faceted needs of disabled children in drawing up care plans.

There are three related assessment pathways which are of particular relevance, namely the Family Support Pathway; the Child Protection Pathway and the Looked After Child Pathway. As with other assessments, under UNOCINI looked after children's plans should be drawn up in partnership with parents and children and young people. Whilst it can be assumed that this should include disabled children, there is a caveat that, *"the age and understanding of the child or young person will likely dictate the degree to which they are able to engage in the assessment process"*(p.78). Although there are recommendations that professionals adopt creative techniques to engage children and young people, this proviso may lead practitioners to exclude some disabled children and young people, particularly those with learning disabilities.

6.4 Families Matter: Supporting Families in Northern Ireland. (DHSSPSNI, 2009)

In accordance with the principles of the ten year children's strategy, *Families Matter* (DHSSPSNI, 2009) emphasises early intervention and universal family support to avert the need for more intensive intervention. Whilst there is a recognised need to work in partnership with children, this policy document views the child within the context of the family and, therefore, partnership working with parents is emphasised.

Families Matter acknowledges varied family structures and also families brought together through fostering arrangements or children cared for within residential homes. Two models are presented in this document, which guide approaches to supporting children and families towards positive outcomes.

The first is the whole child model adapted from Bronfenbrenner's (1994) social ecological model of environment that underpins the UNOCINI assessment framework. This model places the child within the context of their family, carers, communities and broader society. This whole child perspective recognises the network of complimentary and competing influences, which can affect outcomes for individual children including education, health, housing, class, ethnicity, disability and broader societal and political ideology.

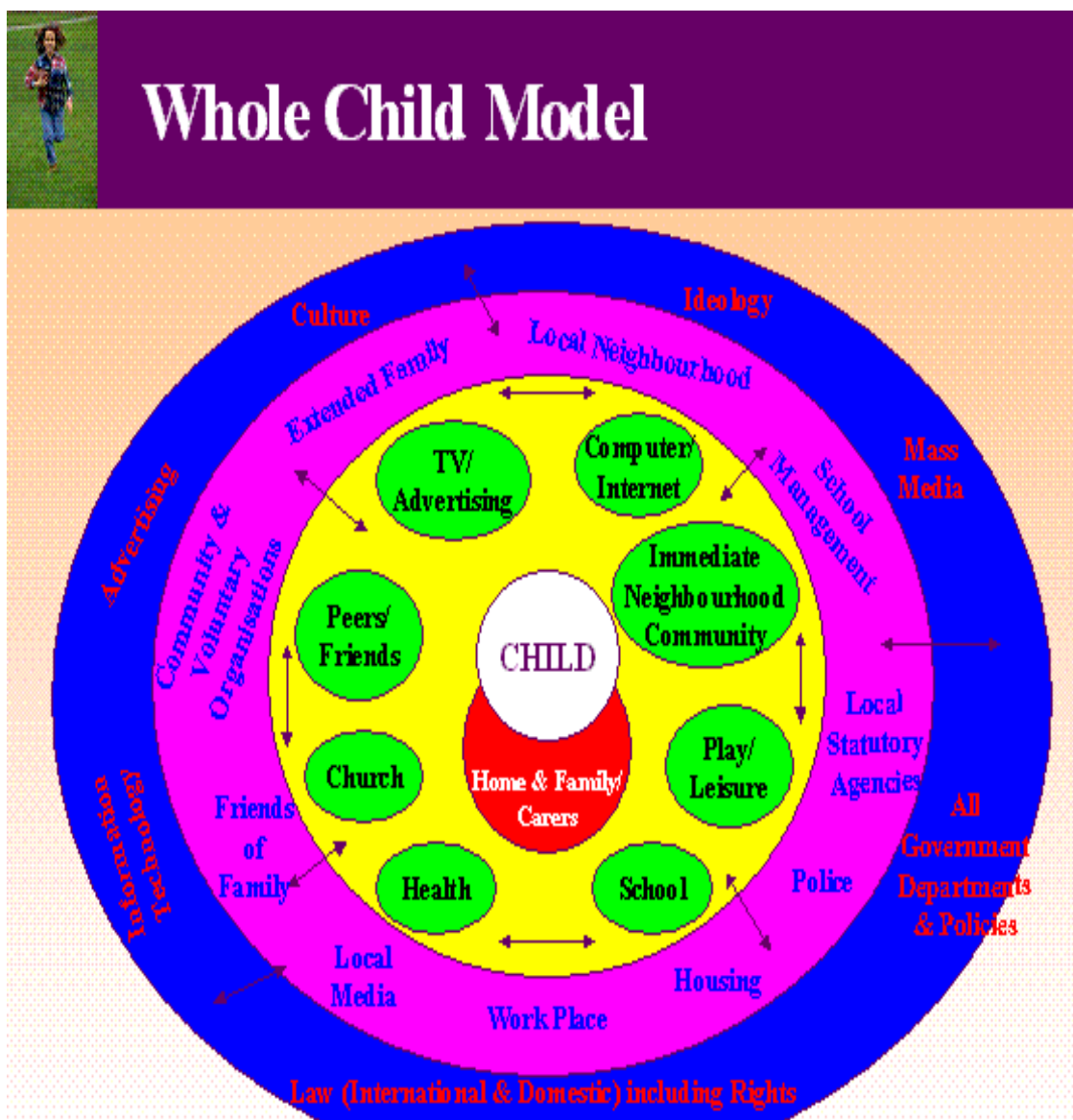


Figure 1: The Whole Child Model (available at: http://www.southernareacsp.n-i.nhs.uk/ni_wide_work.htm)

Secondly, the family support model initially developed from the work of Hardiker *et al.* (1991) and also used within UNOCINI to map four levels of services in response to the needs of children and families. Level 1 provides for generic, mainstream services available to all children and young people such as health care, education and leisure facilities. Level 2 includes services targeted at children who are assessed as being vulnerable, which includes disabled children. Level 3 services are aimed at children in need in the community who are experiencing chronic or serious problems; these services are multi-disciplinary. Level 4 represents support to families or individual children and young

people where the family has broken down temporarily or permanently and Levels 1-3 cannot meet their needs.

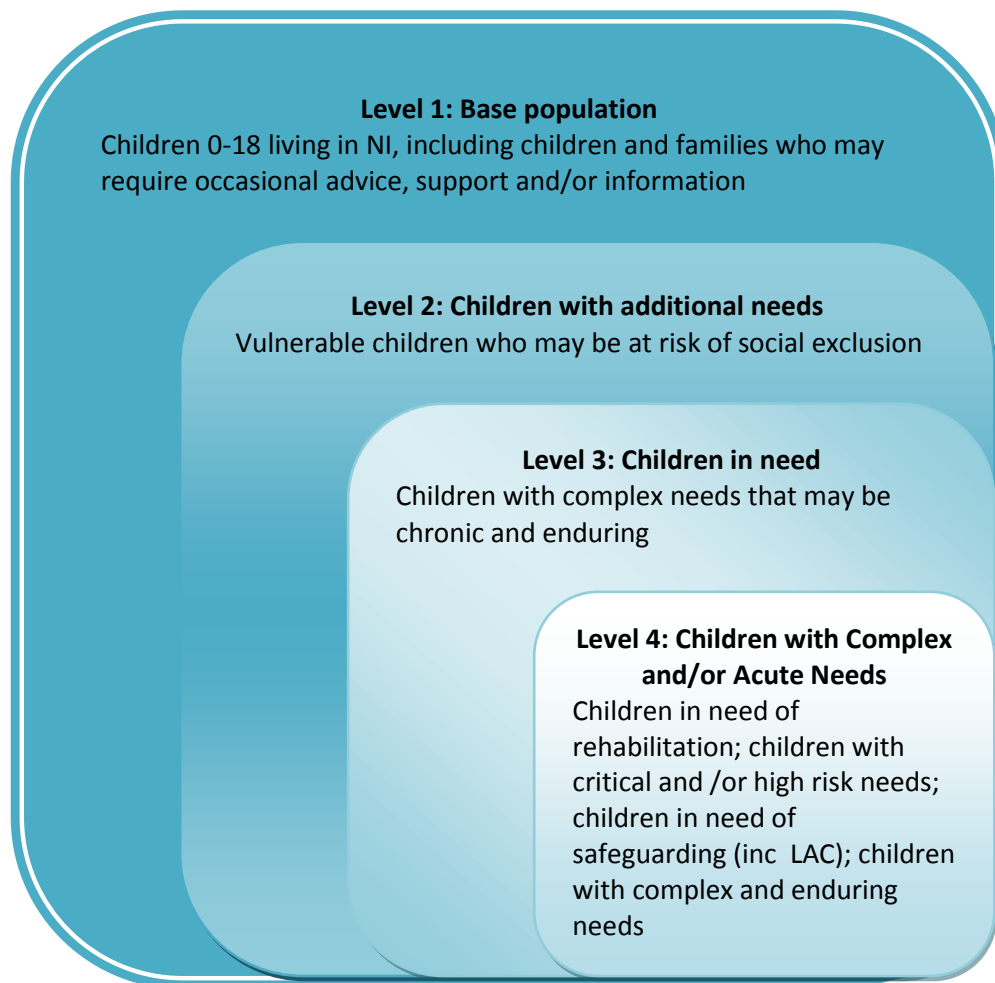


Figure 2: UNOCINI Thresholds of Need Model (DHSSPSNI, 2008a:4)

As a supporting pillar of the ten year children's strategy, *Families Matter* adopts the same six outcomes statements for children and families to measure progress. As it is an overarching document rather than one which deals with specific groups of children within their family context, it makes limited specific mention of looked after children or disabled children. Nevertheless, the principles underlined by the child centred systemic approach and the family support model provides a guiding framework for more specific and targeted policy documents.

6.5 Healthy Child, Healthy Future (DHSSPSNI, 2010)

In May 2010, the DHSSPSNI launched *'Healthy Child, Healthy Future: A Framework for a Universal Child Health Promotion Programme in Northern Ireland; Pregnancy to 19-years'*. This document follows the launch of the Child Health Promotion Programme (England and Wales) (2008), and is the outcome of a local government commission to review and update the Northern Irish child health promotion programme.

The document has expanded the child health promotion focus to span from pregnancy to 19 years of age. The document outlines the universal health promotion programme for all children in NI, including those who are looked after, disabled or require special educational provision; and highlights the UNOCINI framework as the process through which comprehensive assessment of additional need can be made. Resonating with *Families Matters* (DHSSPSNI, 2009), it also places strong emphasis on the role of parents and families in health promotion and preventive strategies; and draws on a whole child approach firmly placing the child in the context of their family and wider environment. There is also an emphasis on early intervention and prevention and on integrated services from both the statutory and voluntary sectors.

Looked after children are a specific focus of this strategy. Quoting Hall & Elliman (2003: 300), the document states that:

"Looked after children are amongst the most socially excluded of our child population. A series of Government reports have highlighted the extent to which health neglect, unhealthy lifestyle and mental health needs characterise children and young people living in public care. Their health may not only be jeopardised by abusive and neglectful parenting, but public care itself may fail to repair and protect health and may even exacerbate damage and abuse" (DHSSPSNI, 2010: pg. 22).

Addressing these challenges with specific reference to disabled children, the strategy highlights the benefits of early identification of impairment, developmental delay or health disorders so services can respond with support and signposting to local resources.

For children identified as being disabled or having special educational needs, the document endorses some key principles that service providers should be mindful of: inclusivity which enables disabled children to fulfil their potential; awareness of children's rights; reduction of health inequalities; and offering choice to children and their families.

6.6 Children and Young People's Strategic Plan 2011-2014 (HSCB, 2011)

The *Children and Young People's Strategic Plan* (CYPSP) was formally established in early 2011 to bring together the planning work of individual HSCTs through their Children and Young People's Committees and the Children's Services Plans. The aim of CYPSP is to develop an integrated, cross-sectoral approach to children's services planning and development with a focus on the six outcomes identified in the 10-year strategy reviewed above. Based on a rights framework, a central aspect is the involvement of children and young people in all associated planning and decision-making processes.

In 2011 the CYPSP published the first integrated regional *Children and Young People's Plan 2011-2014*. Its emphasis is on early intervention and the co-ordination and development of family support services. It makes reference to the development of regional sub-groups and plans focused on, amongst others, disabled children and young people as well as transition for disabled children and young people (CYPSP, 2011: 29).

Based on a rights framework, a central aspect is the involvement of children and young people in all associated planning and decision-making processes. Throughout the document the particular needs of disabled children in relation to their participation and engagement in decision making processes are highlighted. It is recognised that a 'one size fits all' model of participation is not fully inclusive and an 'ask first' approach is endorsed. A variety of methods and approaches to participation are suggested and it is recommended that the choice of method should be tailored to the particular needs of young people, their preferred method and the subject of participation. The document emphasises the value of participation networks which can strengthen advocacy and encourage involvement; the potential for a participation champion for particular groups (again disabled children and those in transition are highlighted) is also raised. The role of

the champion would be to liaise with the Children and Young People's Strategic Partnership and the Participation Network, to identify and avail of opportunities for engaging children and young people, ensure young people's engagement and that they are kept informed of how their input has influenced planning processes, ensure open lines of communication between stakeholders. Whilst the document does mention children and young people who may be vulnerable because of poverty, bullying, bereavement or being affected by domestic violence, there is only one specific mention of looked after children and this relates to the goal that all children should live in safety and with stability.

6.7 Safeguarding of Children and Vulnerable Adults in Mental Health and Learning Disability Hospitals in Northern Ireland (RQIA, 2013)

This document reports on a review of the effectiveness of safeguarding arrangements in mental health and learning disability hospitals across the five HSCTs in NI, including children's learning disability wards and child and adolescent mental health wards.

In reporting on the findings, the document states that past child abuse inquiries had informed the establishment of clear child protection arrangements within HSCTs. There was strong evidence of appropriate structures, governance and joint working arrangements. Policies and procedures specific to looked after children were also in place. In addition, newly established partnerships with children's services provided effective arrangements in relation to leadership, governance, infrastructure, communication and reporting, however, a need for more direct patient feedback was noted.

Staff awareness of abuse was highlighted as being critical to effective safeguarding. The inspection noted that in children's wards, professional roles and staff awareness was good. Wards were proactive in promoting safeguarding using an array of measures to alert staff, relatives and visitors to safeguarding matters. Although the inspection found that not all staff had received appropriate training, including training in risk assessment. The challenges of establishing preventive mechanisms were discussed with the need for: legislation and regulation; policies and procedures; training; awareness raising;

information, advice and advocacy; interagency collaboration; and the involvement of patients and relatives.

The document states that In a one-year period, between November 2010 and November 2011 there were 71 instances of young people under 18 being admitted to adult wards across the five HSCTs. It was noted that best practice recommends that children and young people are accommodated in age appropriate settings. Whilst in practice steps were taken to safeguard minors in adult wards, it was also clear that not all staff in these settings had received child protection training. However, the admission of a minor to an adult ward was regarded as a serious adverse incident and was recorded as such. Overall, whilst all HSCTs had taken positive steps to ensure that adequate safeguarding mechanisms were in place, areas for improvement were identified in each HSCT in relation to all 26 recommendations.

6.8 A Baseline Assessment and Review of Community Services for Children with a Disability (RQIA, 2013)

The RQIA conducted a review of community services for children and adults with learning disabilities across the five Trusts in NI in 2013. This report focused specifically on a baseline assessment of the role, structure and composition of community services for disabled children across the five Trusts in NI. The report describes levels of investment in services, models of service delivery, availability of services across the region and levels of engagement with service users and carers. The prevalent community service model for children was teams mainly comprising social workers and community nurses with the assistance of allied health professionals and clinical psychology staff. There was significant variation in the range and quality of services provided across Trusts and an overlap in professional roles. As the reviewers also reported differences in referral criteria to access disability services, regional eligibility criteria for access to services based on assessed need was recommended to ensure equity of access.

The reviewers found that Trusts had an over-reliance on informal networking rather than using clear clinical pathways in the delivery of services. Moreover, evidence of information sharing between Trusts or teams within Trusts was minimal. The need to

develop shared information systems was highlighted in order to enable electronic access to assessment and treatment plans across disciplines. The commitment of staff delivering services was commended however, there were concerns regarding an absence of vision regarding required service development to meet identified and future needs. All the teams reported high levels of bureaucracy and crisis management. Trusts also faced challenges with regard to the increasing population of looked after disabled children and difficulties in recruiting foster carers for children with complex physical health needs.

A number of areas of unmet need were reported. For example, a reliance on in-patient care in the Iveagh Unit matched with a lack of community based alternatives. The review also noted a reliance on recording interventions but little information on the outcome of interventions and no clear instruments in place to gauge the effectiveness of interventions. Whilst there was evidence of service user engagement, carers expressed concern at lack of access to information about services and frustration about waiting lists for some services, for example, short breaks. The need for access to child-centred, seamless community services for disabled children was noted. Services specific to disabled looked after children feature in the report in relation to three main areas:

1. Engagement of service users

Trusts report positively on engagement with looked after children and young people. In some instances, engagement was further promoted through the voluntary sector organisation, VOYPIC (Voice of Young People in Care). The report emphasised the need to ensure that looked after children and young people and their families (where appropriate) are involved in all aspects of care planning.

2. Short breaks

The report highlighted concerns about an absence of accessible information about available short break services to young people. Flexible short break packages were found to be better developed in some Trusts than in others. A delay in accessing short breaks because of unavailability of the service or long waiting lists was reported to be a source of stress for young people and their families.

3. Transition

The report noted challenges in finding appropriate placements for disabled care leavers who may need on going residential and other supports in adulthood. Looked after processes are identified as a forum to address the needs of young people as the age out of the looked after system. For example, in one Trust adult services are invited to attend looked after child reviews for young people aged 17. The need for a more co-ordinated approach to care planning at transition was highlighted to challenge the model where two separate planning and delivery processes were operating, one by health and social care services and one by education. The Children and Young People's Strategic Partnership Transition Group were reviewing processes regarding transition at the time of writing the report, and the opportunity for more meaningful information and guidance for young people experiencing transition from child to adult services, including those ageing out of the looked after system, are highlighted.

7. Key Disability and Mental Health Policy

This section focuses on policy relating to disability and mental health. A key policy driver in this area is known as **The Bamford Review**. It includes the distinct policy documents discussed below, namely **Equal Lives: Review of Policy and Services for People with Learning disability in NI (2005)** and **A Vision of a Comprehensive Child and Adolescent Mental Health Service (2006)**. The **Equal Lives** report is relevant to both children and adults with learning disabilities and grounded in core principles of citizenship, social inclusion, empowerment, collaborative working and personalized support to individuals. **A Vision of a Comprehensive Child and Adolescent Mental Health Service (2006)** outlines guidance for the development of a responsive, integrated CAMHS and the promotion of preventive mental health strategies and effective treatment of those with mental health needs. In response to the strategic vision laid out in the Bamford reports the DHSSPSNI developed a cross-Departmental **Action Plan for Delivering the Bamford Vision 2009-2011** to protect and preserve the mental health of the population as a whole, to promote better mental health and to improve the lives of people with learning disabilities or mental health needs. The plan includes specific actions and target dates for their completion. The evaluation of this action plan noted achievements and areas still to be addressed. Similarly, the **RQIA Independent Review of Child and Adolescent Mental Health Services (CAMHS) (2011)** highlights service improvements in response to the Bamford Review and recommendation for further service developments.

The **Learning Disability Service Framework (2012f)** sets out explicit standards for the planning and provision of health and social care services to people with learning disabilities. The **Physical and Sensory Disability Strategy (2011-2015)** has a broad focus on the health and wellbeing of people with physical and sensory disabilities and their families with relevance to both children and adults. It addresses service provision, access to specialist equipment and supporting independent living as well as support for parents and carers. Finally, the **Autism Strategy (2013)**, developed in response to the requirements of the *Autism Act (2011)*, addresses definitions and prevalence and proposes a vision of inclusion for people with autism in cultural, social, political and economic life.

7.1 The Bamford Review

An independent review was established in 2002 and progressed until 2007, under the initial Chairmanship of Professor David Bamford. The Bamford review aimed to examine law, policy and service provision for people with mental health needs and those with a learning disability. It also informed the development of a number of reports and documents making recommendations for the review of policy and practice. Two reports inform the work of the present study, firstly in relation to learning disability the *Equal Lives Review of Policy and Services for People with a Learning Disability (2005)* and, secondly, with relevance to children and young people with mental health needs, *A Vision of a Comprehensive Child and Adolescent Mental Health Service (2006)*.

7.1.1 Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland (Bamford, 2005)

The *Equal Lives* report is attentive to a range of issues relevant to both children and adults with learning disabilities. Its underpinning principles include a right to citizenship, the promotion of social inclusion and empowerment, collaborative working and personalized support to individuals. A raft of objectives and recommendations are detailed in the report with a direct focus on improving the lives of people with learning disabilities.

There is also a specific focus on children and looked after children with learning disabilities. The report highlights two key objectives in relation to children, which are: (1) *"to ensure that families are supported to enjoy seeing their children develop in an environment that recognizes and values their uniqueness as well as their contributions to society"* (p.35); and (2) *"To ensure that children and young people with a learning disability get the best possible start in life and access opportunities that are available to others of their age"* (p.41).

The report strongly emphasises early intervention and the need for co-ordinated efforts to identify and address problems through multi-disciplinary services. Information should be made more readily available to parents and children about services and how to access them. The review notes that the rights and views of children and young people with

learning disabilities are often only included as a footnote to wider child focused policy, and their needs are overshadowed by the number and needs of other groups of children and young people.

Children and young people are contextualized within the family setting and prevailing trends in relation to the needs of families with a learning disabled child are highlighted. For example, children with learning disabilities are more likely to live in families who experience poverty, social exclusion and disadvantage than their non-disabled peers; and children with a learning disability are also vulnerable to bullying, which is a significant cause for concern.

The report states that there has been increased statutory and voluntary sector support to families who have a child with a learning disability. There is also a reported increase in the availability and range of short-break options available. Family support is documented as a crucial element in assisting families to continue to care for their son or daughter with learning disabilities at home. Nevertheless, there are a significant number of children and young people with learning disabilities who are looked after. The report highlights the challenges in calculating exact numbers, and makes predictions based on proportionate numbers gathered in one HSC Trust area. It is stated that traditional children's homes have difficulties in adequately supporting children with learning disabilities and further staff training and support is necessary. Secondly, there is a lack of residential foster places for children with learning disabilities and social workers report challenges in meeting the needs of looked after children with learning disabilities.

A number of proposals and recommendations emerge in relation to disabled children who are looked after, including an onus on Trusts to develop family support plans to monitor outcomes and identify unmet need and provision of substantial financial resources to extend the volume and range of emotional and practical support available to families of learning disabled children.

The report also recommends the identification of permanent placements for children and young people who cannot remain with their birth families. The focus of this should be in

relation to developing specialist fostering placements, however, the report does highlight the potential need, "*to commission intensive care provision for children who cannot be placed in family settings*" (p. 45). Finally, there is a recommendation that community based assessment and treatment centres are developed for children and young people presenting with severely challenging behaviour and for those experiencing mental health difficulties.

7.1.2 A Vision of a Comprehensive Child and Adolescent Mental Health Service (CAMHS) (Bamford, 2006)

This report provides guidance for the development of a responsive, integrated CAMHS with the aim of safeguarding the mental health of children and young people. The vision described recommends the promotion of preventive mental health strategies and provision of accessible and effective treatment of those with mental health needs. It is informed by the following principles:

- A comprehensive range of services should be available to children to address their social and emotional needs and promote positive mental health with an emphasis on early identification of mental health need and early intervention;
- Children who have mental health needs should receive individualised services in the least restrictive and most normative environment clinically feasible;
- Family partnerships should be developed and maintained throughout treatment and families should be involved in local policy development;
- Case management should facilitate a multi-disciplinary service approach;
- Particular attention should be paid to those young people in transition to adult services;
- Services should be inclusive and accessible to all children regardless of their learning or physical ability.

The recommendations made in the document are intended to address what is regarded as a long-term neglect of mental health services for children and young people in NI. It is a wide-ranging document, however there are areas of particular significance to the

population who are the focus of the present study. Whilst all children are recognized as children first, looked after children are identified as a sub-group who may have particular needs or vulnerabilities in relation to mental ill health. It is acknowledged that they have a higher susceptibility to developing mental ill health due to the home environment the child has left due to risk of harm or where relationships may be damaged through conflictual, neglectful or abusive situations in the home.

The document highlights the ongoing developmental challenges wrought through damaged attachment relationships and the impact of loss on children who have to leave their home and community to enter the looked after system. Whilst coming into care can bring protective factors there are also potentially contradictory feelings of loss, and the reality that congregate settings, such as residential homes, cannot mirror a family environment.

Whilst a significant need for mental health support is identified for this group, it is also acknowledged that the delivery of effective services is extremely challenging and confounded by a number of factors, particularly for children in residential homes rather than foster placements. Emerging developments such as, the appointment of dedicated posts /teams with a focus of the mental health needs of looked after children are recognition of the need for attention in this area.

However, the report notes that responses are patchy and that there is a lack of coherent planning and investment. Calls have grown for a *'specific mental health strategy for looked after children, which would assist in the development of a tailored and equitable service for this population'* (p20). Service developments relevant to the LAC population highlighted within the document include:

- Close collaboration between social services and CAMHS;
- The development of a range of services best suited to the needs of looked after children and young people to circumvent common challenges such as young people's reluctance to attend formal therapeutic services;

- Additional training and high-level supervision for those who are delivering services to enable purposeful intervention;
- Equitable services should be available across NI and service models should prioritise the needs of looked after children; and
- Comprehensive assessment of need, intervention with the child and carers, and further audit, research and evaluation to enable the development of effective and responsive services.

One specific recommendation (30) is focused on the LAC population with mental health needs, and highlights the need for development of:

“A model that meets the needs of LAC needs to be developed. A cornerstone of the model must be close collaboration between social services and the network surrounding the child. Clinical aspects must include a comprehensive assessment of need, and appropriate evidence based interventions” (p.60).

7.1.3 Delivering the Bamford Vision: The response of NI Executive to the Bamford Review of Mental Health and Learning Disability Action Plan 2009-2011 (DHSSPSNI, 2009)

The *Bamford Action Plan* recognises the vision set out in the *Bamford Review* and underlines a commitment on behalf of the NI Executive to protect and promote the mental health of the population as a whole and to improve the lives of people with learning disabilities or mental health needs. The plan includes specific actions and target dates for their completion to be reviewed and envisaged a 10-15 year timescale for full implementation of its recommendations.

The action plan has a broad focus and is attentive to both adult and children’s services and needs. With a focus on mental health and the promotion of well-being the plan highlights a number of factors relevant to children, namely positive parenting skills, good housing, education, good physical health and safe, caring communities. It is important to reflect that a number of these indicators may be lacking for children who

eventually become looked after and that we know that the incidence of mental health difficulties amongst the looked after population is high.

Taking a life course approach to mental health, the plan notes the importance (among other things) of child-parent bonding as a protective factor against the development of mental ill health in later life. However, the potentially damaging impact of family breakdown and children becoming looked after is not highlighted. Moreover, the relatively high incidence of co-morbidity between learning disability and mental health difficulties is also omitted.

The document contains only one mention of looked after children stating that: *“the mental health needs of looked after children for whom the DHSSPS has lead policy responsibility will also be taken into account”* (p.57). Given the known high incidence of mental health need among looked after children and young people it is surprising that they do not receive more specific attention. In particular, since the Bamford document *A Vision of a CAMHS (DHSSPSNI, 2006)* called for a dedicated CAMHS strategy for looked after children, in order to enable a tailored and equitable service for this population.

The plan notes that there will be nominated leads in mental health and learning disability for both children and adults in the DHSSPSNI, Public Health Agency, Health and Social Care Board and HSCTs as well as Youth Justice and recognises that links between the statutory, voluntary and community sectors should be nurtured. The following objectives for mental health services are contained within the action plan:

- Promoting and preserving mental health and building emotional resilience in the population;
- Developing legislation to promote self-determination in those unable to make decisions for themselves; and
- Improving services for people with learning disability and their families and ensuring better joining up across agencies;

A recovery model, which has two key tools, underpins the proposed vision of mental health services: (1) involving service users; and (2) a stepped model of care. Ten high impact changes are highlighted which revolve around these tools; the central thrust of which are the development of flexible services that are responsive to individual need and the growth of integrated service provision. Joined up working is also highlighted in relation to children and young people with the need to link health and social care with education and CAMHS to enable the potential to achieve best outcomes for children.

In relation to people with learning disabilities, the action plan highlights the need for equal citizenship, inclusion, early intervention, individualised support, health promotion, and forward planning. There is no specific mention in the document of children and young people with a learning disability who are looked after, although much of the content on the general child population could be deemed applicable to looked after children.

7.1.4 Evaluation of 2009-2011 Bamford Action Plan (DHSSPSNI, 2012b)

The evaluation of the Bamford Action Plan 2009-2011 states that whilst the full objectives set in 2009 were not achieved, some progress has been made on many of the actions. Advances in areas relevant to children and young people who are looked after include:

- *Early Years:* The launch of an *Early Years Strategy (0-6)* (reviewed below) to enable improved outcomes for children and their families; and the *Healthy Child, Healthy Future* document (reviewed above) which sets out a regional programme for child health.
- *Short Break Provision:* An increase in the availability of residential short break placements for children with learning disabilities; however, demand continues to exceed supply.
- *Family Support Pathways:* The launch of the NI family support pathway to assess and support all children in need and their carers.
- *Child and Adolescent Mental Health Services (CAMHS):* there has been progress on joint working with the production of a draft joint working agreement consultation completed in January 2010. Guidance within UNOCINI has been strengthened to

reflect mental health needs and the 'Champions' model, expected to develop communication and collaborative working, has been developed in two HSCTs. The evaluation states that it is clear that overall CAMHS are continually improving and further developments will require significant financial investment, which is challenging in the current financial climate.

- *Autistic Spectrum Disorder:* Implementation of the ASD Action Plan has seen improvements in services under the guidance of an ASD forum and lead director in each Trust to oversee service developments. Links have been established between Health and Social Care and Education and work is on-going to forge further links with Youth Justice and District Councils. Finally, a single diagnostic/assessment process is being implemented across NI with the aim of reducing lengthy waiting lists.
- *The Bamford Monitoring Group:* This group highlights where gaps in services remain and areas that require further enhancement. There is some frustration at the proliferation of reports as outcomes from the Bamford Review, rather than the use of resources for service development and improvement. However, the Group endorse the ongoing consultation with service users and their families in relation to the enhancement of existing services and implementation of new initiatives.

7.1.5 Delivering the Bamford Vision: The Response of the NI Executive to the Bamford Review of Mental Health and Learning Disability. Action Plan 2012-2015 (DHSSPSNI, 2012d)

The revised action plan for the period 2012-2015 (DHSSPSNI, 2012d) identified 76 actions for improvement including: promoting positive health, wellbeing and early intervention; supporting carers and families; providing better services to meet individual needs; and developing structures and a legislative framework. The main thrust of the plan centres on departments collaborating with each other to address barriers to social inclusion and participation, and tailor the needs of the individual using a stepped care approach. The plan also outlines the HSC Board's statutory duty to establish and lead the Children and Young People's Strategic Partnership (CYPSP) aimed at improved outcomes for children with emotional and behavioural difficulties or disabilities; and disabled young people

transitioning to adult life. There is no specific mention of looked after children or young people in this document.

7.2 Independent Review of Child and Adolescent Mental Health Services (CAMHS) in Northern Ireland (RQIA, 2011)

This document reports on a review of CAMHS carried out in 2010 by the Regulation and Quality Improvement Authority (RQIA). Improvements in CAMHS since the Bamford Review are noted with increased capacity for in-patient treatment for young people and developments in crisis intervention and the range of services available. However, the review noted that young people are still being admitted to age-inappropriate adult wards. That significant safeguards have been implemented to manage the accommodation of young people in adult wards was noted. However, it was recommended that all CAMHS staff involved in looking after children and young people should be child protection trained.

The review found that not all young people were aware of the availability of advocacy and there were also a number of young people who were unaware of the existence or of the content of a care plan. Community services were valued by young people, rather than in-patient services. However, accessibility of services was difficult in some areas, particularly for those living in rural locations. Access to community and early intervention services are underdeveloped and in some Trusts particular services were unavailable such as crisis intervention or alcohol services. In spite of the above shortcomings some parents and young people did state that CAMHS had been a lifeline in difficult times. However, the consultation did highlight that many young people were unaware of help lines or other support networks, and many did not know of any alternative to CAMHS. The review also noted that young people and their families have limited involvement in the planning and evaluation of services.

Based on this review, the RQIA has made 21 regional recommendations to the five Trusts for improvements to the organisation and delivery of CAMHS, nine recommendations to the HSC Board and one to the DHSSPS. None of these recommendations specifically address the particular needs of looked after children, however, they are applicable to all

children including those who are looked after. Recommendations 3-7 address the provision of information to young people to encourage engagement and understanding; as follows:

- Young people and parents should be included in the processes of planning, delivering and evaluating services.
- Young people should have access to a range of age appropriate resources including the internet, to promote participation and engagement strategies for CAMHS.
- Complaints information should be more accessible in a user friendly format for children and young people to ensure they know of how to make a complaint.
- Children and young people should be able to access advocacy services and trusts should provide appropriate advocacy support.
- Information provided to children and young people about the range and scope of services should be clear, concise and easy to understand (RQIA, 2011: 134-135).

In terms of access to services, the report states that *“CAMHS should be fully integrated within the wider network of children’s services across the Trust to ensure better links and communication across services”* (p.135). Additionally, in relation to access to specialist services recommendations include the further development of specialist Tier 3 services for children and young people with complex needs requiring a specialist response and the management of acute mental health problems in the community wherever possible. Indeed recommendation 19 cautions against placing a young person on an adult ward stating that this should only happen when *“when all other CAMHS alternatives have been considered and deemed less appropriate”* (p.135).

7.3 Child and Adolescent Mental Health Services: A Service Model (DHSSPSNI, 2012c)

In response to Bamford (2006) and the RQIA review (2011) this document sets out future directions for a model of service delivery in relation to CAMHS. for CAMHS in NI which provides a framework for the integration of health and social care services that emphasise prevention, early intervention and recovery. A stepped care model is proposed

to ensure services are matched to service user need and a whole systems approach that effectively links primary care, child health, social care services and specialist CAMHS.

The need for cross-sectoral collaborative working is emphasised alongside the re-organisation of child and adolescent mental health services. Central to the re-organisation is an integrated Children's Service System bringing together all areas of children's health and social care services and in partnership with education, youth justice the police and relevant voluntary sector organisations.

Part of the vision for the CAMH service model is that those who are at risk are identified quickly and in a non-stigmatising manner. Amongst those who are more vulnerable and identified in this document are looked after children and those with a learning disability. In relation to the latter, it is noted that *"dedicated services should be available to provide assessment and appropriate interventions for such children"* (p.15). It is not however clear whether such services would be under the banner of CAMHS or another specialist provider such as psychiatric services. Given the agenda of inclusion the former is preferable.

7.4 Learning Disability Service Framework (DHSSPSNI, 2012f)

The *Learning Disability Service Framework*, produced by the DHSSPSNI, sets out explicit standards for the planning and provision of health and social care services to people with learning disabilities and is one of a number targeted at people with specified health or social care needs. The framework is intended for use by commissioners, statutory and non-statutory sector providers and the RQIA in commissioning, measuring and monitoring services. It aims to: strengthen the integration of health and social care services; enhance social wellbeing by identifying risk and instigating preventative strategies; and promote evidence-based practice and multi-disciplinary working in order to be cognisant of the range of factors affecting the health and well being of people with learning disabilities (such as, socio-economic position, education or housing). The framework also places an emphasis on taking service users' views into account in developing and monitoring standards.

The *Learning Disability Service Framework* is organised around a life course approach as well as in relation to generally applicable principles such as inclusion. It identifies three levels of services. At Level 1 are generic services, which can be accessed and used by all members of the community including those with a learning disability. Level 2 encompass reasonable adjustments to generic services without which people with learning disabilities may be disadvantaged; these include advocacy and the provision of accessible information. Level 3 are services targeted at people with learning disabilities and delivered within learning disability programmes. These include family support, day activities and CAMHS, among others.

Standard 5 address the issue of effective communication and information about available services as a core part of service planning and delivery. The rationale for these standards is a high number of people with learning disabilities and their families experiencing communication difficulties and challenges in accessing comprehensive and understandable information. Effective communication enables the identification of need, the opportunity to enable people to reach their potential and the chance for early intervention and effective intervention in response to need. The availability of a named staff member to assist people in understanding information on services is recommended.

Section 5 of the document details four standards which relate specifically to children and young people with learning disabilities and places an emphasis on early intervention, personalised care, action planning, wraparound services and a seamless co-ordinated approach for children and families. A child-centred model guides the approach alongside an ethos of enabling children with learning disabilities to have the same opportunities and life experiences as other children.

Concerns are detailed about the current state of service provision which is said to often lack, *"responsiveness and flexibility required to ensure that children and young people with a learning disability enjoy equal access to the full range of supports that are required to effectively address the needs rising from additional health problems they have. This can result in them receiving care and treatment that is less than optimum, is poorly*

coordinated and sometimes delivered in settings which are not developmentally appropriate."(p.73).

Standard 13 is directly relevant to looked after children with learning disabilities. It states: *"Any child or young person who cannot live at home permanently should have their placement and accommodation needs addressed in a way that takes full account of their learning disability"(p.76).*

In support of this standard is the statement that children and young people who cannot live with their birth families are supported within living arrangements that are sufficiently expert to meet their individual needs and promote permanence in children's lives. However, it is also stated that many of these children and young people will have challenging behaviour, specific health needs or autism. This is likely a narrowing of the population which suggests an assumption that the reason for not living with the birth family is related to the child/young person's impairment rather than child protection concerns.

The learning Disability Service Framework is a living document which will be subject to review and updating in response to new and changing priorities and the introduction of new performance indicators.

7.5 Physical and Sensory Disability Strategy (2011-2015) (DHSSPSNI, 2012g)

The *Physical and Sensory Disability Strategy* (DHSSPSNI, 2012g) has a broad focus on the health and well-being of people with physical and sensory disabilities and their families. It is relevant to both children and adults and is attentive to service provision, access to specialist equipment and supporting independent living as well as support for parents and carers.

The strategy highlights a number of thematic areas which require improvement, these include the development of personalisation in service planning and provision, the availability of accessible information, the provision of advice and advocacy, greater availability of suitable short breaks and for older persons increased access to day

opportunities and housing options. The Strategy includes an action plan, which details plans in relation to each of these areas.

In relation to children and young people two specific strategic priorities are identified. Strategic Priority 8 focuses on access to appropriate support to enable disabled children to reach their full potential and promote equal opportunities for other children within the family. Strategic Priority 9 addresses the needs of disabled parents to enable them to fulfil their parenting responsibilities. However, there is no reference to the care and support needs of looked after children with physical or sensory disabilities, nor the family support strategies that may enable children to remain within their own homes.

From a regional perspective, the strategy highlights the value of multi-agency collaborative working and person-centred approaches to the planning and delivery of services. There is also a move towards a standardised approach to assessment and documentation across Trusts to facilitate collaboration and sharing of resources across Trusts so as to increase equality of access to existing resources and more efficient use of available funding.

7.6 The Autism Strategy (DHSSPSNI, 2013)

This document was developed as a response to the requirements of the *Autism Act (2011)* and is the outcome of collaborative working with practitioners, people with autism and their families. It is a cross-departmental initiative; in addition to Health and Social Care there was collaboration with Education as well as higher Education, training and Employment, Welfare, Housing, Justice, Community and Voluntary sectors, Arts, Leisure and Sports. The Strategy provides a definition of autism which forms the parameters of the ensuing document, noting that the term autism is used to denote Autistic Spectrum Disorder, Asperger's syndrome, Rett's Syndrome and other pervasive developmental disorder not otherwise specified.

The Strategy reports that in NI there are approximately 5000 children and 1,500 adults with autism. It draws on the principles of the UNCPRD and promotes the inclusion of people with autism in cultural, social, political and economic life. Key objectives are to:

increase awareness of rights, choices and life opportunities to people with autism; support the ongoing development of high quality services; encourage an integrated approach to planning, commissioning and management of services; and ensure clear and measurable actions as an outcome of the strategy.

Strategic priorities are identified and grouped thematically. Of particular interest to this review is Strategic Priority 5, Children, Young People and Family which states the need to:

"Ensure that children and young people with autism and their families have access to effective and appropriate support, where required, to help them with the challenges of family life." (p.30).

This is a broad and fairly general statement and is attributed within the document as being derived from the *UNCRPD*, the *10 year Children's Strategy and Families Matter*. Further, the Strategy recognises the importance of multi-agency working across statutory, voluntary and community sectors to offer the best possible future to children and young people with autism.

Strategic priorities detailed are supported by an action plan, which has a related timescale for implementation and named responsible agency. In relation to Strategic Priority 5, the stated action is to: provide joined up, timely support services to meet the needs of families with children with autism, with the DHSSPSNI as the lead with input from the Department of Education (DENI). The successful implementation of this action is to be measured against evidence of joint working arrangements between the HSCTs, autism services and education; as well as evidence of the provision of support to children with autism, their families and siblings. However, the parameters of this action are broad without specific focus on particular support or service issues, which may be of concern to children and their families. There is no mention of family support services, short breaks or indeed looked after children with autism and the particular needs they and their families may have.

8. Key Youth Justice Policy

The section reports on the review of the youth justice system in NI and subsequent implementation plan which highlights key areas for improvement including efforts to address the over-representation of looked after children and young people within the youth justice system and the mental health needs of children and young people within the youth justice service. However, there is still a failure to acknowledge disabled looked after children who are especially vulnerable and likely to require access to targeted support.

8.1 Review of Youth Justice System in NI (Department of Justice, 2010)

In 2010, a review was launched by the Minister of Justice into the youth justice system in NI. The review assessed the current arrangements for responding to youth crime, whilst also making recommendations for future improvements. Northern Ireland, like other parts of the UK, has a separate justice system for children aged 10-17 years inclusive aimed at preventing re-offending, the protection of the public and securing the welfare of the child. The review highlighted the different stages and processes within the youth justice system including: early intervention; police action; the public prosecution service; bail and remand; youth conferencing and youth court; custody; and, re-integration and rehabilitation of youth offenders (DoJ, 2010). The report listed a number of key recommendations including the prioritisation of young people in the planning process, upholding the paramountcy of the welfare of the child and enhancing complaints procedures for young people. In relation to looked after children, the report also makes the following specific relevant recommendations:

- Recommendation 8 - The development of an appropriate range of supported (and if necessary secure) accommodation, accessible at short notice, to reduce to an absolute minimum the use of Woodlands as a place of safety
- Recommendation 19 - Looked after children should no longer be placed in custody... where this would not have been an outcome for children in the general population

- Recommendation 22 - All agencies working with children and young people should improve their understanding of special needs and the impact these have on those specific groups over-represented in the youth justice system and in custody. The DHSSPS should lead in developing better assessment, inter-agency information exchange and cross-referral mechanisms alongside more specialised interventions.
- Recommendation 24 – The CYPSP should become strategic, multi-agency forum through which regional and local priorities are agreed (DoJ, 2010: 171-177).

The report acknowledges the need to address the over-representation of looked after children and young people within the youth justice system and also highlights required improvements to meet the additional support needs of young people with learning disabilities or mental health needs. Young people who have a dual experience of being disabled and looked after may require additional support and guidance navigating the youth justice system. They may also require significant help re-adjusting and integrating into society following contact with the justice system, however, this report neglects to consider the particular needs of these young people.

8.2 Youth Justice Review Implementation Plan (Department of Justice, 2013)

In 2013, the Department of Justice published an implementation plan addressing the recommendations of the Youth Justice Review. A range of improvements were noted including the development of joint DHSSPS / PSNI guidelines on appropriate operations and procedures for looked after children (DoJ, 2013). Similarly, with regard to the additional needs of specific groups of young people within the justice system, the DHSSPSNI, DOJ, YJA and PSNI are working on a number of initiatives to address the issues faced by the over-presentation of young people with SEN within the justice system (DoJ, 2013: 38). Finally, discussions are ongoing regarding the best way to operationalise a multi-agency forum, however the CYPSP have identified three key strategic priorities including mental health, education and early intervention to prevent offending/re-offending (DoJ, 2013).

9. Key Education Policy

Education is a central platform in enabling children and young people to achieve their potential. The Department of Education NI (DENI) aims to ensure that the conditions for each child to fulfil their educational potential are available. Some children need additional support and amongst these looked after children are identified as at particular risk of not meeting their educational potential. Five policy documents are considered in this section.

Care Matters (2007) recommends the introduction of a Personal Education Plan for each looked after child with the express purpose of improving educational outcomes for this group.

Every School A Good School (DENI, 2009) takes an inclusive, child-centred perspective whilst recognising the impact of the child's wider experiences in their familial and social environments on their engagement with and experience of education. **The Early Years Strategy** (DENI, 2010) highlights the importance of the early years as a foundational time for children, which can impact on the rest of their lives. It states that interventions in the early years can reduce the impact of social or material disadvantage. These documents are both referring to all children rather than having a specific focus on disabled children, however the latter are included in the broad policy described.

In 2012, DENI launched a **consultation focused on Special Educational Needs (SEN)**. This UK wide document is critical of current SEN approaches which are described as outdated, complicated and stressful. It proposes a re-working of the system to enable improved longer-term outcomes for children and young people, challenging low aspirations for children with SEN and seeking to ensure that every child fulfils their potential.

In accordance with the duties laid out in the Disability Discrimination Act (1995), DENI submitted a **Disability Action Plan (NI) 2012-2013** to the Equality Commission. It details plans for the promotion of positive attitudes toward people with disability and the encouragement of their participation in public life through the critical arena of education.

9.1 Personal Education Plans (Care Matters, 2007)

With a view to improving educational outcomes, the Care Matters (DHSSPSNI, 2007) document (reviewed in section 6 above) recommended the introduction of a Personal Education Plan (PEP) for every looked after child. PEP's focus on the whole child/young person and aim to optimise learning opportunities within the home environment, school and local community.

A PEP is an overarching education plan which combines other educational plans such as the Individual Education Plan and a Statement of Educational Needs. PEP's are designed to assist looked after children to reach their potential and to promote positive outcomes in education. The PEP forms part of the legal care plan for looked after children and provide a record of academic progress and achievement. As personalised plans they take into account young people's social and emotional development and set out and review short term targets in support of longer term educational plans and aspirations held by the young person.

The aim of the PEP is to maintain a firm focus on education as a process and as a key outcome area for looked after children and young people. They also inform young people's decisions and plans as they prepare for the transition out of care post 18 and seek to attain further education and employment goals as young adults.

9.2 Every School a Good School: The Way Forward for Special Educational Needs and Inclusion (DENI, 2009)

The *Department for Education (DENI)* is responsible for pre-school settings, schools and the youth service and promotes the development of the whole child in relation to their social well-being and development so they are equipped with the knowledge, skills and experience to fulfil their aspirations and reach their full potential. At the time of publication of *Every School a Good School* (DENI, 2009) there were over 1000 children and young people with *Special Education Needs* (SEN) who were looked after, out of a total of 58,827 with a SEN. The reasons for being assessed as having an SEN are many, diverse and dynamic. This report highlights inconsistencies in assessment and levels of support available across the five Education and Library Boards (ELBs).

Every School a Good School adopts a child-centred model, which recognises the broad spectrum of education as well as wider familial, social and environmental networks. This report focuses on the meaning of inclusion for children with SEN, which goes beyond the physical location of a child's placement and extends to their full participation in the curriculum and social life of their educational settings. In considering inclusion, the diverse needs of children should be considered, and this is particularly the case for children who are looked after and may experience a range of barriers to their social and educational inclusion. Beyond this reference, and general signposting to Care Matters in relation to the education of looked after children, there is no further specific reference to the educational needs of this population.

9.3 Early Years Strategy (DENI, 2010)

The *Department of Education NI (DENI)* published their *Early Years (0-6) Strategy* in June 2010. It underlines the importance of the early years in children's lives as having a foundational influence on the rest of their lives and that interventions early in life can reduce the disadvantage gap produced by social and environmental conditions such as poverty.

Early years education is intended to prepare children for primary schooling, not solely in relation to education but also in terms of their social and communication skills, physical development and health. This report recognises the importance of the parent or primary carer in the early years of a child's development however, it does not highlight the difficulties children may face through separation from parents by becoming looked after. The particular needs of looked after children are not addressed in the Early Years Strategy.

The report highlights the need to identify children in need of additional assistance to ensure that relevant provision is targeted in an appropriate and timely manner. However, disabled children receive brief mention in this document in relation to appropriate interventions to enable disabled children to have equal access to education.

9.4 Support and Aspiration: A New Approach to Special Educational Needs and Disability: A Consultation (DfES, 2012)

This UK wide document provides a critique of the current SEN system and provides a vision for revising the system. The report states that the current SEN system is out-dated, fraught with complications, unfit for purpose and stressful for children and families. The new vision proposed aims to enable better longer-term outcomes for children and young people, challenge the *“culture of low expectations”* and place *“sharper accountability on schools to make sure that every child fulfils his or her potential.”* (DfES, 2012:16). The emphasis is on: early identification of SEN and appropriate intervention, choice and control to children and families; clear and effective communication between education authorities, parents and carers (to include those with parental responsibility for looked after children); the removal of unnecessary bureaucracy; the transfer of power to local communities and providers; and the promotion of higher expectations of achievement for children with SEN.

The document highlights issues relating to multiple assessments of disabled children which can result in inconsistent and overlapping support plans (p.21). Proposals for a new single assessment process as part of an ‘Education, Health and Care Plan’ are made, to replace the statutory SEN assessment and statement and bring together the range of supports accessed by disabled children and young people with SEN. However, there is no specific reference as to how this single assessment might impact on or be adapted to the needs of looked after children who are reported to be three-and-a-half times more likely to have a SEN compared with all children. (p.22)

Looked after children are likely to experience developmental challenges, and this report recommends that steps are taken to identify SEN as early as possible to enable appropriate support and early intervention. The report proposes the strengthening of links between education services and social care services for looked after children to promote more consistent and streamlined educational support.

The important role of the voluntary and community sectors in enabling a more holistic approach to supporting looked after children with their broad educational needs is also

recognised. In addition, family support is viewed as critical for promoting the best outcomes for children and young people with SEN who are looked after, therefore clear and regular information to parents/carers and including foster parents or a named support worker, are recommended in the document to be of critical importance.

In May 2012, the Minister for Education presented a follow up policy paper on the Review of SEN and Inclusion to the Committee for Education. This policy paper addresses some of the concerns expressed during the consultation period and clarifies the final proposed legislative and policy changes. The concept of Additional Educational Needs (AEN) is promoted, although the legislative definition of SEN will not change. The Minister confirmed that the broad range of policies for other AEN groups, including looked after children, will also remain. Among other proposed changes, the policy paper confirms that each school will be expected to establish a Personal Learning Plan (PLP) for students with SEN or AEN to replace Individualised Education Plans and these will have a greater emphasis on targets to be achieved and the necessary adjustments and interventions required to ensure appropriate progress. The Department will issue a revised statutory Code of Practice on SEN and Inclusion for consultation to provide guidance for all schools on how to implement proposed changes and deliver effective teaching and learning to all children facing barriers to learning.

9.5 Disability Action Plan (NI) 2012-2013 (DENI, 2012)

DENI submitted a *Disability Action Plan* to the Equality Commission in 2012 which details plans on how to address the duties outlined in the Disability Discrimination Act (1995) to promote positive attitudes towards disabled people and encourage the participation of disabled people in public life. Planned measures include the protection of disabled children within education through anti-bullying strategies combined with awareness raising to encourage better understanding of the needs of disabled children. There is also an emphasis on developing the needs of particular groups such as those with autism, or disabled children having the opportunity to be taught through the Irish language. Compliance matters are addressed, in that schools will be required to make reasonable adjustments within an eight week period in relation to assessed needs of individual children, and that assessments are carried out on school premises to ensure that they

adhere to the standards laid out in the *Disability Discrimination Act*. Child protection and pastoral care is also highlighted with the Education and Training Inspectorate given the undertaking of reporting on these matters. There is no specific mention of the needs of disabled children who are looked after or their particular circumstances and needs.

9.6 Advancing Shared Education (OFMDFM, 2013)

In July 2012 the Education Minister John O'Dowd appointed a Ministerial Advisory Group on Advancing Shared Education. The group's remit was to advise the Minister on how best 'shared education' might be taken forward to meet the needs of all learners and to provide for children and young people from a variety of backgrounds to be educated together.

Importantly, the definition of 'shared education' is inclusive of all groups and all sectors and involves the organisation and delivery of education so that it:

- Meets the needs of, and provides for the education together of, learners from all Section 75 categories and socio-economic status;
- Involves schools and other education providers of differing sectoral identity and ethos, management type or governance arrangements; and
- Delivers educational benefits to learners, promotes the efficient and effective use of resources, and promotes equality of opportunity, good relations, equality of identity, respect for diversity and community cohesion.

Of particular relevance to disabled children in schools are the following among the 20 recommendations:

- Schools and other educational institutions are to be designated as public authorities under Section 75 of the Northern Ireland Act 1998 and thus are required to comply with the statutory duties to promote equality of opportunity and good relations.

- The Education and Skills Authority, in conjunction with the Equality Commission for Northern Ireland, should establish a unit to provide training, produce support materials and to advise schools and educational institutions in relation to preparing, implementing and monitoring the equality schemes they would be required to produce under Section 75.

The Department of Education should undertake a review of how shared education, and the enhanced collaboration between mainstream schools, special schools and educational support centres, can most effectively meet the needs of children and young people with disabilities, those with emotional and behavioural difficulties and those with special educational needs. The review should focus on the development of effective models for collaboration that can:

- Ensure, wherever possible, that children and young people are taught in mainstream schools; and
- For the small minority of children and young people where mainstream schooling is not suitable, that they have meaningful opportunities to learn with children and young people in mainstream school environments.

10. Key Trends

Consistent themes are evident throughout the range of documents reviewed above, from international human rights instruments to domestic legislation and policy. Central principles with direct impact on disabled children and young people are those of equality, social inclusion and anti-discrimination. This is evident both in the spirit of documents as well as in practice guidance and policy recommendations.

A common theme across much of the policy reviewed is the centrality of the family in children's lives and the foundational impact of family circumstances and wellbeing on children's upbringing. Whilst the family is recognised to be of central importance, the best interests of the child are emphasised. The 'whole child' model is particularly evident in child and family policy, underlining the diverse and manifold factors that impact on children's lives and which are interactive and mutually reinforcing. In terms of service style there are common themes within the legislation and policy documents. These include early identification of need and timely intervention, multi-agency working and person-centred service provision. Improved outcomes for children and young people are reported to result from approaching service delivery in these ways.

The importance of seeking the views of children, young people and their families is enshrined in human rights instruments and is a central feature of legislation and policy documents. It is highlighted as a requirement in the provision of services to children and young people, and the need to make suitable adjustments to enable those who do not use speech to communicate is emphasised.

These themes can be identified across the range of policies reviewed in health, social care and education. Indeed there is a high degree of consistency in approaches across the range of documents, including disability, child, and looked after children's policy. However, looked after disabled children and young people do not feature strongly in the spectrum of policy and legislation reviewed. Consideration of law and policy relating to this population requires a read across a range of documents and policy areas. There is a danger, therefore, that their particular needs and experiences may be ignored and could require more holistic consideration in current policy.

Key recurring themes identified in this review of legislation and policy include: equality, social inclusion and anti-discrimination; a whole child, systemic approach; a family-centred approach; early intervention and multi-agency working; and the participation of children, young people and their families. These themes are discussed in further detail below with examples drawn from reviewed documents.

10.1 Equality, Social Inclusion and Anti-Discrimination

The central principles guiding the international human rights treaties are based on the promotion of equality, social inclusion and anti-discriminatory attitudes and practices. These can be seen as foundational concepts, which underpin local legislation and policy.

Legislation in the UK and NI specifically provides for the promotion of equality and anti-discriminatory practices through the *Human Rights Act (1998)* and the *Northern Ireland Act (1998)*. These guiding principles are also apparent throughout the policies reviewed and are frequently cited. For example, *the Equal Lives* report (DHSSPSNI, 2005) recognises that children with learning disabilities and their families have an increased likelihood of experiencing social exclusion, are more likely to be disadvantaged through poverty and be vulnerable to stigmatisation and discrimination. Likewise, within education policies it is noted that outcomes for children with SEN are likely to be much more compromised than for other children, and this vulnerability is further increased amongst those who are also looked after. Indeed being a looked after child is reported to create a range of disadvantages, including vulnerability to mental health challenges, social exclusion and marginalisation (*DHSSPSNI, 2010*).

Principles of inclusion are emphasised in children's policy; for example the 10 year children's strategy emphasises the need to elicit and include children's views and perspectives about things that affect them. Moreover, that disabled children are afforded the same opportunities as all children in their social, educational and family lives is underlined. Children's rights instruments directly influence these standards, primarily the UNCRRC, the principles of which are integrally woven into much current children's policy.

Given the noted experiences of inequality and exclusion amongst both disabled children and looked after children, a clear imperative to advocate for disabled looked after children within a policy agenda is well recognised and evidenced.

10.2 Whole Child, Systemic Approach

The policy documents reviewed here widely recognise the multiple and layered influences on children and young people together with the inter-connectedness of outcomes across different domains. *Families Matter (2009)* emphasises the whole child model within the context of families, schools, communities and the wider society. Outcomes are related to differing influences. For instance, abusive or neglectful parenting (family influence) may increase vulnerability to social and emotional challenges for young people who may become looked after and, thus, exposed to a range of other vulnerabilities including insecurity, educational challenges and stigmatisation. Alternatively, a well supported family with access to early intervention services and living in an inclusive community environment may enable a disabled child and their family to thrive.

The child is, therefore, located within their whole environment, with recognition that discrete factors impact on one another. Outcomes for children should, thus, be understood as inter-related and multi-layered. *The Child Poverty Strategy (2011)*, for example, emphasises the inter-connectedness of social, health, environmental and educational matters on the production and perpetuation of poverty. It reinforces understanding that deficits in one area are likely to impact on child outcomes in another area.

10.3 Family-Centred Approach

A consistent trend throughout the legislation and policy is the centrality of the family in the lives of children. One of the guiding principles of the *Children (NI) Order (1995)* states that the family is the best environment in which to raise a child, with the welfare being paramount.

Families Matter (DHSSPSNI, 2009) and *Care Matters (DHSSPSNI, 2007)*, both closely related to the overarching policy framework of the *ten year children's strategy* and

Transforming Your Care (DHSSPSNI, 2011), firmly locate the child in the context of the wider family. The family is portrayed as integral to the social foundation within *Care Matters* and, for those children who cannot remain with their birth families, this policy recommends family based alternatives, such as kinship care, fostering or adoption. *Families Matter (DHSSPSNI, 2009)* is attentive to those families with higher level needs. With a strong emphasis on family support, early and intensive intervention, the idea that families are central to children's well being is reinforced including supporting those on the 'edge of care' to remain with their families through appropriate timely and family support.

The *Equal Lives (2005)* report notes the additional challenges faced by families who have a child with learning disabilities and highlights the impact on child outcomes. Poverty, social exclusion and stigma may all impact on the health and wellbeing of children and young people. Bamford's *Vision of a Comprehensive Child and Adolescent Mental Health Service (2006)* also highlights the importance of families, recommending that family support plans are developed to identify unmet need amongst vulnerable children and young people and the provision of additional resources to extend the support available to the families of these children. There is also an emphasis within policies on the importance of partnership working with families and the need to build relationships with parents and listen to their views.

There is a central conflict in thinking about child welfare and the importance of family in relation to the looked after child, and this is played out in the policies reviewed. On the one hand the value of a family upbringing is repeatedly reinforced. Yet in the worst circumstances the family can be the greatest source of harm to a child. The tension for services in balancing the best interests of children to remain within their birth families, whilst safeguarding them against potential harm is apparent. Vigilance to the potential danger that the focused emphasis on family centred care overrides the rights of the child should also be ongoing.

The challenges wrought through negative social, financial and environmental influences upon families who have disabled children are well documented. Whilst policy can address

these matters, the challenge of transforming policy into action in the context of current resource constraints that impact on service availability and capacity, remains.

10.4 Early Intervention, Multi-Agency Working and Person-Centred Services

There are several recurring trends in service style across the policies reviewed. Early intervention is recommended across the board as enabling the best outcomes for children and young people. Early intervention within families and schools is identified as a potentially beneficial approach to improving long-term outcomes. In disability policy, the Bamford Review (2006) emphasises improved outcomes through early intervention to address mental health needs as well as enhanced life chances for people with learning disabilities through early identification of need and early supportive intervention.

Multi-agency working is another consistent policy theme. This resonates with the notion of the whole child and family-centred working, as it endorses the inter-connectedness of differing areas of the child's life. Children's health is likely to impact on their educational experience and multi-agency collaborations and strategies have the potential to counteract any negative effects. Looked after child reviews call for input from the range of intervention services involved in the child's life across education, health and social care, as well as acknowledging input from the voluntary sector. Education policy calls for a single assessment process, which includes input again from the range of involved professionals so as to obviate the need for multiple assessments and support conversations between all involved with a particular child.

Early intervention and multi-agency working are both focused around a third trend in current policy, person-centred care and support. This is sometimes described as personalisation and is a shift towards services designed around the assessed needs of individuals. Person-centred support takes into account the whole-child within their social and familial environment and draws on a multi-agency approach to deliver the range of services required by individuals. Relatively recent legislation putting in place access to direct payments which can be used to purchase support and services, is indicative of the commitment to the delivery of services in a person-centred manner. The need for bespoke mental health services for looked after children to enable a more person-centred

approach is a key recommendation of the Bamford review. Likewise, *'Every School a Good School'* states that decisions about school placement and educational support should be taken on a person-centred basis, taking into account the unique needs and abilities of each individual child. However, once again it may be that school placement availability will have a stronger influence than will assessed need and individual choice.

Person-centred support is contentious, as challenges exist due to the unavailability of particular options. For instance, we know that children are best brought up in family environments however, there is a lack of foster care placements for disabled children who cannot remain with their birth families. Whilst the most appropriate, person-centred response may be to find an alternative family setting for the disabled young person, the unavailability of such an option may necessitate a compromise.

10.5 Participation of Disabled Children, Young People and their Families

The need to engage children and young people in relation to matters that affect them is reiterated throughout the legislation and policy documents. Likewise, there is an emphasis within policies about the importance of partnership working with families and the need to build relationships with parents and listen to their views.

Historically, decisions were made about and for children and young people, but in the present policy context the inclusion of children and young people both in terms of receiving information and giving their opinions is now accepted as best practice. There is a requirement for disabled children and young people to be consulted and included in decisions and the UNCRC (1998) recommends the use of a range of methods of communication to effectively engage disabled children and young people. This requirement is reiterated in NI children's policy and legislation. However, disabled children and young people are still less likely to have their views about important matters in their lives sought and heard; and are less likely to be included in decisions or receive adequate, meaningful information. This is particularly the case for those with learning disabilities and mental health needs due to capacity concerns.

Some steps are being taken to address this and a recent report from Disability Action's Centre on Human Rights for People with Disabilities (Harper *et al.*, 2012) acknowledges the ongoing efforts on the part of the *Commissioner for Children and Young People* and the OFMDFM funded *Participation Network* in relation to promoting the participation of children and young people more generally.

10.6 Connecting Threads and Greater Challenges

The documents reviewed above are drawn from differing domains, have a range of purposes and are addressed to differing audiences. However, there are strong connecting threads woven through them, as described in the themes above, from an international rights perspective through to local policy initiatives. The principles in the global rights-based documents are underpinned by the promotion of equality and prevention of discrimination and these same concepts also form the bedrock of much of the NI policy reviewed.

The need to produce legislation and policy to promote improved life chances for vulnerable groups and altering their exclusion and marginalisation is a recognition of and response to the social environment in which inequality and social exclusion are experienced. Local rights-based legislation and policy highlight a range of positive steps forward in the lives of children and young people, protections and opportunities for improved life chances for looked after children and better outcomes across a range of areas for disabled children including those with mental health needs. The central tenor of policies, strategy documents and legislation, show a high degree of convergence, and the recent raft of new policy documents attentive to children, disability, social care, family policy and education are part of the same conversation. However, significant gaps relating to disabled looked after children specifically, in policy and strategy documents remain. Children's policy often pays only brief attention to the particular needs and circumstances of disabled children, whilst children are often a subsidiary concern of disability policy. The needs of disabled children who are looked after receive very few mentions within policy documents.

However, this group, whilst perhaps relatively small in number compared to the general child or general looked after population, do appear to be over represented in relation to the broader statistics. The numbers of looked after children with mental health difficulties is particularly high.

The complexity of life challenges, and multiplicity of life experiences and the poverty of outcomes reported for this group of vulnerable children draws attention to the need for bespoke policy focused on addressing their specific and diverse needs.

Such policy should take account of the range of challenges faced by these children across a range of care experiences and disabling social barriers impacting on their lives. To alter disabling social attitudes and respond to the rights agenda for disabled children who are looked after requires imminent direct attention. Such policy can then be firmly embedded in the broader children's social care agenda for action and change.

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