

# Children with Disabilities Strategic Alliance

## Manifesto

(Review and Update 2012)



Children with Disabilities Strategic Alliance

The Children with Disabilities Strategic Alliance (CDSA) brings together organisations from across the children's sector and the disability sector. It is jointly chaired by Children in Northern Ireland (CiNI) and Disability Action (DA).

CDSA wants to ensure that policy impacting on the lives of children and young people with disabilities is informed by their needs and circumstances.

Through this Manifesto<sup>1</sup> we aim to:

- Promote the rights and best interests of children and young people with a disability;
- Raise awareness of the exclusion experienced by children and young people with disabilities in their daily lives; and
- Recommend actions that will help address the barriers they encounter.

### **UN Convention on the Rights of the Child**

The United Nations Convention on the Rights of the Child (UNCRC) was adopted by the General Assembly in 1989<sup>2</sup>. The UK subsequently signed the Convention in 1991. In October 2008, the UN Committee on the Rights of the Child delivered its most recent consideration of implementation of the Convention by Great Britain and Northern Ireland.

### **UN Convention on the Rights of Persons with Disabilities**

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted by the General Assembly in December 2006. The UK signed the treaty at the first opportunity in March 2007 and ratified the Convention on the 8th June 2009. However it noted a reservation, among others, to Article 24 which requires states to deliver an inclusive education system.

As a measure of the importance and status of the implementation of the legal rights of persons with disabilities, the UNCRPD was ratified by the EU on 23rd December 2010.

The EU has a Ten-Year Disability Strategy for 2010 to 2020 which will shape policy for the next decade.<sup>3</sup>

The Office of Disability Issues coordinated the UK Government's response, along with the devolved nations, to the UNCRPD Committee on how it is fulfilling obligations and reported on it in July 2011.<sup>4</sup>



Throughout the paper, where relevant to children with disabilities, reference is made to both UN Conventions and to supplementary recommendations and guidance issued by the Committee on the Rights of the Child.<sup>5</sup>

## **The Social Model of Disability**

The UNCRC requires that all States Parties utilise the Social Model of Disability when designing services to include children with disabilities. Article 1 of the Convention states:

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

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.

Proactive efforts are essential to bring about the required shift in societal attitudes away from the medical model of disability to embrace the social model and commit to removing barriers faced by disabled children and young people, ensuring their full participation in all aspects of their lives.

## Contents

## Page Number

<b>Cross Cutting Issues and Key Asks</b>	<b>5</b>
Priority funding for disabled children and young people	5
Research on the needs and circumstances of disabled children and young people	7
Accessing services	9
Accessing mainstream public services	9
Accessing disability specific services	10
Empowering children and young people with disabilities and their families	12
Training and information for those working with children with disabilities	12
Information and advice	13
Active participation in decision making	14
Bullying	17
Full and active inclusion of children with disabilities in strategic policy initiatives	18
<b>Theme 1: Family Support (Including Support for Siblings and/or Disabled Parents)</b>	<b>20</b>
Family support	20
Short breaks	22
Child care	24
<b>Theme 2: Support at Key Stages</b>	<b>26</b>
Early identification and intervention	26
Access to early years' services	28
Transition services and support	29
Leaving hospital	30
Leaving school	31
Becoming independent	33

<b>Theme 3: Health and Well-Being</b>	<b>35</b>
Mental health of disabled children and young people	35
Physical health of disabled children and young people	38
Support provided to children with complex health needs	39
Personal relationships and sexual health	40
<b>Theme 4: Access to and Participation in Play, Recreation, Leisure, Sport and Cultural Life</b>	<b>43</b>
<b>Theme 5: Poverty and Welfare Reform</b>	<b>46</b>
Poverty	46
Welfare Reform	47
<b>Theme 6: Education</b>	<b>49</b>
Disability and special educational needs	49
Educational attainment	50
Pre-school provision for children with disabilities	51
Further Education and Higher Education provision for young people with disabilities	53
Suspension and expulsion	56
Alternative Education Provision (AEP)	57
Transport to and from school	58
Assessment and statementing of children with special educational needs	59
Limited participation of children and young people in decision making in education settings	62
Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO)	64
Access to curriculum and examinations	66
<b>Theme 7: Protection from Abuse</b>	<b>68</b>
<b>References</b>	<b>71</b>

## Cross Cutting Issues and Key Asks

The Children with Disabilities Strategic Alliance (CDSA) has identified a number of cross-cutting issues which must be addressed as a priority by the Government in Northern Ireland:

- Priority funding for disabled children and young people
- Research on the needs and circumstances of disabled children and young people
- Accessing services
- Empowering children and young people with disabilities and their families
- Full and active inclusion of children with disabilities in strategic policy initiatives

### Priority funding for disabled children and young people

#### Issue:

There is evidence to suggest that children with disabilities and their families are being adversely and disproportionately impacted by Government spending decisions with funding for some disabled children's services being withdrawn or reduced.<sup>6</sup>

As is evident from Budget 2011-15 there is a clear lack of disaggregated analysis of Government spending on disabled children and young people across all areas; health, social care, education, arts, leisure and sports.

#### What is needed:

Government must make disabled children and young people a priority in Programme for Government and Budget processes. Supports and services that are essential to ensuring children with disabilities can enjoy their rights must be protected. Sufficient investment must also be made available to meet the assessed needs of children and young people with a disability and their families.

It is essential that proposals to reduce or remove funding to services and support are properly assessed to identify impacts on the promotion of equality of opportunity for disabled children, young people and their families and appropriate mitigating action taken to minimise any adverse impacts.

The work being undertaken by the Children and Young People's Strategic Partnership to plan for health and social care services for children, including disabled children is welcome.

A broad strategic review of all aspects of services for disabled children and young people is required to ensure that the current configuration of disabled children's services meets their needs; and that gaps in current provision and areas of unmet need are identified<sup>7</sup>. The review should be undertaken in partnership with the disability and children's sector and ensure that the role played by the sector in developing innovative, child and family centred approaches is recognised and adequately resourced.

There must be greater transparency and accountability for spend on services for children and young people with disabilities across Government. The Executive must develop and implement a robust mechanism for disaggregating, tracking and monitoring spend on children to ensure maximum return on investment.

### **Did you know?**

The UK Children's Commissioners have noted that despite central, devolved, and local Government commitments that service reforms or spending decisions will not disproportionately affect disabled children there is growing evidence to the contrary. The Commissioners have recommended that services and support that enable disabled children to enjoy their rights must be protected from cuts in public expenditure.<sup>8</sup>

### **Positive Developments:**

The Children and Young People's Strategic Partnership has established a regional group on disabled children alongside an advisory/reference group of young people with disabilities.

### **Children's rights context:**

UN Committee on the Rights of the Child General Comment No.9 (2006) 'The Rights of Children with Disabilities' states children should be a priority in the budgets of State parties and further that:

"Resources allocated to children with disabilities should be sufficient – and earmarked so that they are not used for other purposes – to cover all needs

including programmes established for training professionals working with children with disabilities such as teachers, physiotherapists and policy makers as well as for education campaigns, financial support for families, income maintenance, social security, assistive devices and related services.” (para 20)

The UN Committee on the Rights of the Child state that “even where the available resources are demonstrably inadequate, the obligation remains for a State party to strive to ensure the widest possible enjoyment of the relevant rights under the prevailing circumstances ... whatever their economic circumstances, State parties are required to undertake all possible measures towards the realisation of the rights of the child, paying special attention to the most disadvantaged groups”.<sup>9</sup>

The Committee has further called for children to be made visible in budgets commenting “no state can tell whether it is fulfilling children’s economic, social and cultural rights, to the maximum extent of available resources, as it is required to do under article 4, unless it can identify the proportion of national or other budgets allocated to the social sector, and within that, to children, both directly and indirectly. Some states have claimed it is not possible to analyse budgets in this way. But others have done it and publish annual children’s budgets”.

## **Research on the needs and circumstances of disabled children and young people**

### **Issue:**

Despite some recent examples of research, local evidence or information about the needs and circumstances of children and young people with a disability and evidence about the relevance or appropriateness of interventions, remains limited.

There is a lack of research on the prevalence of different conditions. Research and information is crucial to accurately informing the development of evidence based strategy, policy and service initiatives that can ensure equality of opportunity and the positive inclusion of children with disabilities.

Existing area-based approaches to gathering information on need and to delivering funding could disadvantage geographically dispersed and complex populations, such as children with a disability and their families.

Schedule 2 of the Children (NI) Order 1995 required the establishment of a register of disabled children. Despite a full regional project report having been completed a number of years ago on the disabled children register, the Health and Social Care Trusts have not moved forward on this matter.

### **What is needed:**

The Executive must develop and implement a cross Government data gathering system that allows for the collation and monitoring of disaggregated data on all aspects of the lives of children and young people with a disability. Such data would allow for a comprehensive assessment of the level and extent of inequalities experienced by children with disabilities in accessing and benefiting from public services and ensure that policies and resources effectively enable the promotion of equality of opportunity.

It is welcome that the Autism Act 2011 has placed a statutory duty on the Health and Social Trusts to provide the DHSSPS with data on the prevalence of autism in their respective areas. Health and Social Care Trusts should examine how processes and mechanisms to gather data on prevalence of autism could support, inform and guide the gathering of prevalence data on a wide range of disabilities/conditions.

Area based approaches must give due regard to ensuring that geographically dispersed, complex populations, such as children with disabilities and their families are given fair and equal consideration in planning and commissioning services and delivering resources.

### **Did you Know?**

NICCY has recommended that within Government there is a need for more systematic collection of qualitative and quantitative data on the experiences of, and outcomes for, children and young people from vulnerable and marginalised groups.<sup>10</sup>

Equality Commission NI Guidance to Public Authorities on Implementing Section 75<sup>11</sup> of the Northern Ireland Act requires public authorities to undertake an audit of inequalities to identify the range of key inequalities which the discharge of their functions is intended to address. The audits inform the development of action plans which must detail how a public authority will undertake the promotion of equality of opportunity across the nine equality categories.

## Children's rights context:

The UN Committee on the Rights of the Child is still concerned at the absence of a nationwide mechanism to collect and analyse data on the areas covered by the Convention. The Committee recommends that the State Party “establish a nationwide system such that disaggregated data is collected on all persons under 18 years for all areas covered by the Convention, including the most vulnerable groups, and that these data are used to assess progress and design policies to implement the Convention”. (para 18-19)

The UN Committee in General Comment No 9 (2006) The Rights of Children with Disabilities indicated that it is necessary for State parties to “set up and develop data gathering mechanisms, which are accurate, standardized and allow disaggregation, and which reflect the actual situation of children with disabilities.” (para 19)

Article 31 of the UNCRPD (Statistics and data collection) states that countries must collect information about people with disabilities, with the active involvement of people with disabilities, so that they can better understand the barriers they experience and ensure full implementation of the UNCRPD .

## Accessing services

This issue looks at the experiences of disabled children and young people in:

- Accessing mainstream public services
- Accessing disability specific services

## Accessing mainstream public services

### Issue:

Although the right of disabled children and young people to access the same services as other children has been accepted and recognised across Government Departments in the Promoting Social Inclusion (PSI) report on Disability<sup>12</sup>, disabled children and young people are still not routinely able to access and benefit from public services in the same way as their peers. There is a general lack of awareness amongst public service providers on what they need to do to provide inclusive and welcoming services that meet the specific needs of disabled children and young people.

Attitudinal barriers are often the greatest hurdle that disabled children and young people have to overcome to access their rights, enlarge their choices in life or expand their level of independence.

The failure of agencies, services and departments to work in a holistic manner or in partnership compounds the barriers faced by disabled children and young people.

Lack of staff training specific to the requirements of disabled children and young people can also hinder inclusion in service provision.

Physical barriers continue to exist for disabled children and young people in both internal and external environments and can also hinder access to services.

### **What is needed:**

A high level commitment by public bodies to facilitate and monitor the promotion of positive attitudes and the inclusion of disabled children and young people including the identification and implementation of reasonable adjustments, training for staff, and the development of targeted initiatives or programmes.

It is essential that service deliverers improve physical accessibility to their premises and also ensure that services are accessible to disabled children and young people.

### **Children's rights context:**

In its 2008 Concluding Recommendations the UNCRC expressed concern that there was no comprehensive national strategy for the inclusion of children with disabilities in society and recommended that such a strategy be developed. (para 53)

The Committee also recommended that Government undertake awareness raising campaigns on the rights and special needs of children with disabilities, to encourage their inclusion in society and prevent discrimination and institutionalisation.

## **Accessing disability specific services**

### **Issue:**

Disability specific policies, strategies and services have not traditionally been developed with the distinct needs of children and young people in mind. The location

and delivery of disability specific services may not always take account of how best to fit in with other aspects of the person's life, such as going to school, having friends or enjoying social activities.

The current over reliance on diagnosis and eligibility criteria as a means to determine access to services results in some disabled children being excluded from the services they require and reinforces the medical model of disability.

The establishment of a disability sub-group as part of the Children and Young People's Strategic Partnership should go some way to ensuring that the needs of disabled children and young people are reflected in the planning, commissioning and provision of health and social care. It is important, however, to recognise the range, diversity and extent of needs of disabled children and young people and to ensure that individuals or groups are not excluded from the support they and their families need through over simplification, the tightening of eligibility or the failure to ensure that selected interventions are relevant, appropriate and accessible to disabled children and young people and their families.

### **What is needed:**

The development of holistic, child and family centred disability specific services, with strong links to health, social care, education, leisure, sports and community services.

### **Did you know?**

The Bamford Review stated that the needs of children with a learning disability were "a footnote, an afterthought" within Health and Social Services (HSS) programmes of care. Such programmes were dominated by the needs of adults and they had not benefited from initiatives to improve children's experiences or from measures focused on learning disability.

Service frameworks<sup>13</sup>, which are designed to help improve the way health and social care is planned, commissioned and delivered, have been produced for mental health, and for cancer prevention, treatment and care. A service framework on learning disability should be available in the near future. Those produced to date include specific standards in relation to children and young people.

From April 2011, no children should wait longer than 13 weeks for assessment for autism following referral and a further 13 weeks for commencement of specialised intervention.<sup>14</sup>

## **Empowering children and young people with disabilities and their families**

This issue looks at the barriers experienced by disabled children and young people around:

- Training and information for those working with children and young people with disabilities
- Information and advice
- Active participation in decision making
- Bullying

## **Training and information for those working with children with disabilities**

### **Issue:**

Professionals across public bodies working with children with disabilities and their families often lack confidence, skills and experience in communicating with disabled children and young people and in making reasonable adjustments.

### **What is needed:**

A rights-based training programme to raise awareness of the rights and distinct needs of children and young people with disabilities should be developed and implemented, involving disabled children, their parents and carers throughout the process. The training programme must ensure that staff can support children and young people with disabilities to enjoy equal access to and benefit from the full range of mainstream public services, while also availing of specialist and targeted interventions as necessary. Training should be part of initial pre-qualification and induction as well as core to ongoing professional development programmes.

### **Did you know?**

Research conducted by the Patient Client Council<sup>15</sup> identified a need for training and information for HSC staff to help respond to people with disabilities and those with very specific needs.

The UK Children's Commissioners have stated that professional training programmes for staff working with disabled children must be developed and implemented as soon as possible.<sup>16</sup>

### **Children's rights context:**

The UN Committee on the Rights of the Child in its most recent Concluding Observations on UK implementation of the UNCRC<sup>17</sup> considered the specific situation of children with disabilities and recommended to Government that it:

“Provide training for professional staff working with children with disabilities such as medical, para-medical and related personnel, as well as teachers and social workers.”

“Undertake awareness-raising campaigns on the rights and special needs of children with disabilities to encourage their inclusion in society and prevent discrimination and institutionalisation.”

## **Information and advice**

### **Issue:**

Families consistently report great difficulties in getting the information they need, including information about available support services. Accessible, age appropriate information for children and young people with disabilities is rarely produced.

### **What is needed:**

Disabled children and young people and their families need independent, timely, relevant and accessible information at key times, for example, at the point of diagnosis and at other major transition points to enable them to make genuinely informed choices. Key frontline staff must be equipped to effectively signpost disabled children and their families to information and support services.

Information and advice services targeted at parents and families must be available in a range of formats and accessible to disabled parents. The Family Support NI<sup>18</sup> website provides details of a wide range of organisations that provide help and support to families. It is essential that the information on the database is relevant and accessible to the families of disabled children and young people and that a targeted engagement strategy is developed and implemented to ensure that

they are aware of, and can access and benefit from, the information held on the database.

### **Did you know?**

The Bamford Monitoring Group<sup>19</sup> has identified that there is a need to address, at a regional level, the major deficit in the provision of advice and information services for those who use and rely on mental health and learning disability services. Consideration should be given to a model similar to those in Great Britain such as NHS Choice or NHS 24.

Contact a Family Research<sup>20</sup> which was conducted with families with disabled children reported that in Northern Ireland 79% of families surveyed felt most isolated when their child was first diagnosed. Contact a Family recommend that as part of a single assessment process and plan there is an obligation on all frontline professionals such as GPs, teachers and health visitors to identify and effectively signpost all parents/carers to sources of financial, social and emotional information, advice and support.

### **Children's rights context:**

UNCRC Article 23(3) (Respect for home and the family) states:

“... State Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.”

## **Active participation in decision making**

### **Issue:**

More needs to be done if disabled children and young people are to be listened to and actively involved in decisions about their life. Advocacy services and complaints procedures are not routinely accessible to disabled children and young people. Children, young people, families and carers are not always recognised and respected as partners with professionals in decision making processes.

## What is needed:

Innovative, targeted approaches are required to ensure that children and young people with disabilities, including those with communication difficulties, mental health, learning disability or complex health needs, are listened to and responded to. Disabled children and their families should be included and valued as equal and active partners in the development of policy and the planning and design of services which aim to meet their needs.

Effective, equitable and independent advocacy services which champion and respond to the distinct needs and circumstances of disabled children and young people should be developed and funded throughout Northern Ireland. Legislation, policy and commissioning arrangements on advocacy support must be inclusive of, and accessible to, children and young people with a disability.

Public bodies when developing and implementing their Disability Action Plans, as required by the Disability Discrimination Order 2006, should ensure they include promotion of the participation of children and young people with disabilities in the life of the public body when carrying out all of its functions, including the delivery of services etc.

The Northern Ireland Human Rights Commission and the Equality Commission for Northern Ireland have been designated as the independent monitoring and reporting mechanism for the UNCRPD as required by Article 33 (2) of the Convention. It is essential that in monitoring and reporting the importance of involving and engaging children with disabilities and their representative agencies is recognised and responded to as required by Article 33 (3).

## Did you know?

Contact a Family<sup>21</sup> has called on the Executive to ensure that parents/carers have a voice and are partners in making decisions about services that help them lead a more ordinary life and feel less isolated.

The UK Children's Commissioners<sup>22</sup> are seeking to ensure that advocacy services are provided for the most marginalised and vulnerable children, including disabled children in all four jurisdictions before 2014. To address the inconsistent provision of advocacy both within and across the four jurisdictions, they recommend the introduction of new legislation or a demonstrable action to implement and realise provisions that have already been made in law.

## Children's rights context:

Article 12 of the UNCRC states:

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

“For this purpose the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative body, in a manner consistent with the procedural rules of natural law.”

UNCRC General Comment No. 9 (2006) The Rights of Children with Disabilities states:

“It is essential that children with disabilities are heard in all procedures affecting them and that their views be respected in accordance with their evolving capacities... Engaging them in such a process not only ensures that the policies are targeted to their needs and desires, it is also a valuable tool of inclusion since it ensures that the decision making process is a participatory one. Children should be equipped with whatever mode of communication to facilitate expressing their views. Furthermore, State parties should support the development of training for families and professionals on promoting and respecting the evolving capacities of children to take increasing responsibilities for decision-making in their own lives.” (para 32)

Article 33 (National implementation and monitoring)<sup>23</sup> of the UNCRPD states:

1. The countries will make sure that there is at least one position in the government that will be responsible for making sure that the Agreement is put into practice.
2. The countries will make sure that within the government, they create an independent institution that will monitor how the Agreement is being put into practice.
3. Non-governmental organisations, especially people with disabilities and their organisations, will be fully involved in overseeing how the country puts the Agreement into practice

## Bullying

### Issue:

Young people with disabilities are particularly vulnerable to bullying, with the effects being felt well into adulthood. Despite the statutory obligation requiring all schools in Northern Ireland to develop anti-bullying policies, schools do not regularly and consistently monitor bullying of children and young people with disabilities.

### What is needed:

Children with disabilities must be involved in the development, implementation, monitoring and review of school anti-bullying policies. School anti-bullying policies should outline procedures for tackling bullying of disabled pupils. The level and the extent of disabled bullying must be monitored and reported. Staff, including student teachers, must be adequately trained so that they have the necessary knowledge and confidence in identifying, responding to and monitoring such incidents of bullying.

### Did you know?

Mencap's 'Don't Stick it, Stop it!' research in 2007 found that amongst children and young people from Northern Ireland, England and Wales:

- Eight out of ten children with a learning disability are bullied
- Eight out of ten children with a learning disability are scared to go out because they are frightened they might be bullied
- Six out of ten children with a learning disability had been physically hurt by bullies
- Five out of ten children who had experienced bullying said that they stayed away from places where they have been bullied in the past
- Nearly four out of ten (36%) children surveyed said that the bullying didn't stop when they told someone
- Nearly three out of ten (27%) children surveyed were bullied for three years or more<sup>24</sup>

Children with a disability and those with visible medical conditions can be twice as likely as their peers to become targets of bullying.

The Disablist Bullying Task Group of the Northern Ireland Anti-Bullying Forum has defined disablist bullying as hurtful, insulting or intimidating behaviour linked to a perceived or actual disability.<sup>25</sup>

The Northern Ireland Anti-Bullying Forum has produced 2 leaflets on tackling bullying for parents of disabled children and young people with a disability.

A Report for the Standing Conference on Teacher Education North and South<sup>26</sup> has highlighted disablist bullying as one of the most challenging and complex issues which student teachers are facing in the modern classroom. The report highlights there is a strong argument for the topic of disablist bullying to be made part of Initial Teacher Education and Continuing Professional Development courses.

### **Children's rights context:**

The UN Committee of the Rights of the Child in its 2002 Concluding Observations noted its concern at the widespread bullying in schools. The Committee recommended that Government take measures and adopt adequate mechanisms and structures to prevent bullying and other forms of violence in schools and include children in the development and implementation of these strategies.

In its 2006 General Comment on the Rights of Children with Disabilities the Committee observed that school bullying is a particular form of abuse that can target children with disabilities. The Committee urged schools to take all measures to combat school bullying and pay particular attention to children with disabilities providing them with the necessary protection while maintaining their inclusion into the mainstream education system. (paras 42 and 43 (e))

### **Full and active inclusion of children with disabilities in strategic policy initiatives issue:**

Children and young people with disabilities are largely invisible in many strategic policy initiatives. They tend to fall between disability services and children's services and therefore their unique and specific circumstances and needs as children with disabilities are often overlooked. This can result in children with disabilities and their families becoming invisible when key decisions are made about establishing the need for, planning and delivering services, including public services.

## What is needed:

Across Government there is a need for co-operation and joint working on strategic policy initiatives, planning, commissioning and delivery arrangements to ensure positive outcomes for all children, giving explicit consideration to the particular needs of children with disabilities and their families. Data and information, including performance indicators, must be sufficiently disaggregated to allow for the monitoring of equality of access; the uptake and benefit from mainstream services by children with disabilities; whilst also ensuring access to the extra support and/or the targeted and specialist services that may also be required to deliver on outcomes.

The establishment of a regional sub-group on the rights and needs of Disabled Children and Young People by the Children and Young People's Strategic Partnership is a welcome development.

## Children's rights context:

The UN Committee on the Rights of the Child in its most recent Concluding Observations on UK implementation of the UNCRC<sup>27</sup> considered the specific situation of children with disabilities. The Committee expressed concern that:

- a. There is no comprehensive national strategy for the inclusion of children with disabilities into society;
- b. Children with disabilities continue to face barriers in the enjoyment of their rights guaranteed by the Convention, including the right to access to health services, to leisure and to play;

The Committee also made a number of specific recommendations including that Government:

- d. Develop a comprehensive national strategy for the inclusion of children with disability within the society.

# Theme 1: Family Support (Including Support for Siblings and/or Disabled Parents)

This theme looks at what needs to be done to improve:

- Family support
- Short breaks
- Child care

## Family support

### Issue:

The vast majority of children with disabilities live at home and are supported by their families.<sup>28</sup> Support for families is critical, particularly at times of transition such as; birth; hospital to home; getting ready for school; leaving school; becoming more independent. Unfortunately, such support is not consistently and routinely available to all families when required, resulting in a postcode lottery in relation to access to family support services.

### What is needed:

Family focused, accessible, targeted interventions and processes are required if parents and families caring for a disabled child or young person are to access the same support and services as other parents, as well as the additional tailored support around the parent or child's disability. Early intervention programmes and initiatives must be accessible to all parents, including parents with a disability. It is important that there is a strategic and co-ordinated approach, which is inclusive and flexible enough to respond to the needs of all disabled children and young people, including those with complex and multiple disabilities.

This additional support should encompass a range of options, for example, access to specialist advice and information on financial entitlements; entitlement to a named key worker around the time of diagnosis; support from other parents/families in a similar situation; support for siblings; and support that recognises lifelong caring responsibilities.

The Department of Health, Social Services and Public Safety (DHSSPS) investment in family support services has created a strong infrastructure of vital support to families that must be protected going forward. It is essential that the intensive and complex support needs of children and young people with a disability and their families, particularly at times of transition, are recognised and prioritised within future funding for family support services. More and better support should be made available for parents with a disability in their parenting role.

The ongoing development and roll out of locality based Family Support Hubs must address the difficulties faced by families of disabled children and young people in accessing the support they need; and result in better co-ordination of locally based family support, early intervention and prevention services. It is essential that the Hub model gives explicit consideration to the distinct needs of disabled parents and children and young people with disabilities, ensuring equal access to local mainstream family support as well as the additional support that families caring for a child or young person with a disability may require.

The development of appropriate evaluation frameworks for family support initiatives and interventions is crucial. It is essential that the views of children and young people with a disability and their families on effective family support interventions are reflected within the framework, with specific outcomes, indicators and performance measures identified to capture the experience and views of children and young people with disabilities and their families.

### **Did you know?**

The DHSSPS is currently reviewing 'Families Matter', the Regional Family and Parenting Strategy which aims to empower and assist parents to be confident and responsible in helping their children to reach their potential.<sup>29</sup>

Contact a Family research<sup>30</sup> reported on the impact of isolation on families with disabled children. 70% of families felt the lack of support from statutory services contributed to feelings of isolation. These families have to fight to get support and often the support available is insufficient or inappropriate.

### **Children's rights context:**

UNCRC Article 18 states "... Government shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children".

UNCRC General Comment No. 9 (2006) The Rights of Children with Disabilities states:

“Children with disabilities are best cared for and nurtured within their own family environments provided that the family is adequately supported in all aspects... In this context, support should be extended to children who are affected by the disabilities of their caregivers.” (para 41)

UNCRC Article 23 Respect for home and the family<sup>31</sup> states: Children who have any kind of disability should have special care and support so that they can lead full and independent lives. (UNICEF)

## Short breaks

### Issue:

The absence/lack of community based services for children with disabilities, particularly those children with complex needs, continues to place increased demands on parents/carers who are the main care givers.

This can lead to family stress and breakdown, deteriorating health of parents/carers, increased risk of children being placed in care and deteriorating emotional and social development for disabled children and their siblings.<sup>32</sup>

### What is needed:

The report by the Bamford Monitoring Group on short breaks<sup>33</sup> identified the need to develop, commission and expand the provision of flexible breaks across Northern Ireland; to improve information on Direct Payments, short breaks and Carers Assessments; to improve co-ordination between children and adult teams; to accommodate families caring for relatives who are known to both teams; and to facilitate and monitor access to Direct Payments.

Disabled children and their families need a menu of child focused and family directed short breaks to include planned breaks and emergency respite. Such options would allow parents/families a break from caring responsibilities and allow parents to spend time with other siblings. Appropriate short breaks also have positive impact on the lives of disabled children allowing them the opportunity to increase independence, experience new relationships and environments.

Government must clearly identify the proportion of funding allocated to disabled children and families for short breaks and ensure that families caring for a disabled child have equal access to funding allocated for short breaks.

Commissioners of services should ensure that procedures and systems which define, map and determine eligibility for short break services reflect the needs and circumstances of disabled children and young people and their families across Northern Ireland.

### **Did you know?**

In Northern Ireland, the Government's target of providing 200 new or enhanced respite packages in the Bamford Action Plan 2009-11 to benefit people with a learning disability was reduced to 125 additional respite packages in the DHSSPS Priorities for Action (2010-11).<sup>34</sup>

The DHSSPS is exploring ways to provide a clearer and fuller picture of current and future respite provision and need.<sup>35</sup>

The DHSSPS is working to draft guidance and standards for disabled children receiving short break/respite care in children's homes and in host family situations.<sup>36</sup>

An evaluation by Every Disabled Child Matters (EDCM) of the duty on local authorities to provide short breaks in England and Wales (Children and Young Person's Act 2008) demonstrated the positive impact of the legislation including an increase in numbers of local authorities producing high quality eligibility criteria, an increase in the number of areas developing local offers for short breaks and the greater involvement of disabled children, young people and their families in local decision making on short breaks.<sup>37</sup>

### **Children's rights context:**

The UN Committee on the Rights of the Child (2008) 'Concluding Observations - United Kingdom of Great Britain and Northern Ireland' expressed concern at:

"... the high percentage of children with disabilities [in alternative care]" (para 44) and recommended that Government "assess why so many children with disabilities are in long term institutional care and review their care and treatment in these settings." (para 45)

UNCRC General Comment No. 9 (2006) The rights of children with disabilities states:

“Family support services should include different forms of respite care, such as care assistance in the home and day care facilities directly accessible at community level. Such services enable parents to work, as well as relieve stress and maintain healthy family environments.” (para 41)

## Child care

### Issue:

The childcare situation for families of disabled children is stark. Families with disabled children face considerable difficulties in finding accessible, appropriate childcare. Finding alternative care arrangements as disabled children become older and leave school can prove to be even more difficult for families. The additional costs associated with disability can mean that families caring for disabled children have fewer resources than other families to pay for the child care they need. Amongst families with disabled children there is a low level of awareness and take up of financial assistance such as that of the childcare element of Working Tax Credit, childcare vouchers and Direct Payments. Research also highlights concerns regarding the entitlement to Direct Payments of parents whose children have complex medical needs associated with their disability.<sup>38</sup>

Many parents who have children with disabilities and/or special needs do want to work but simply cannot work.<sup>39</sup> A survey by Employers for Childcare Charitable Group<sup>40</sup> revealed that within two parent households only 27% of such families were in a situation where both parents work full time. Accessible childcare is vital to help parents work and to enhance the opportunities of disabled children to learn and reach their potential during their early years.

### What is needed:

A strategic approach to childcare policy and provision must ensure that families with a disabled child can access high quality, flexible, affordable childcare to allow them the same opportunities as non-disabled families. There is a need for adequate and appropriate training of childminders: both specialist training to meet the needs around specific disabilities and generic training around disability awareness.<sup>41</sup> A targeted awareness raising campaign is required to ensure parents are supported to access the financial support available to help with childcare costs.

In setting minimum standards on childminding and daycare, Government must explicitly recognise and provide for the rights and needs of children with a disability and/or special needs.<sup>42</sup>

### **Did you know?**

Research conducted by Employers for Childcare Charitable Group<sup>43</sup> points to a shortage of specialised appropriate childcare. Only 34% of survey respondents reported using formal childcare. Amongst parents of children with disabilities there is a strong reliance on informal childcare (66%), with grandparents being the most common choice (35%). Parents spoke of the lack of suitably trained staff to manage their child's needs within formal childcare, while 16% of respondents to the survey said that childcare providers would not accept their child because of their disability.

### **Children's rights context:**

UNCRC Article 18 requires Government to render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children. This includes taking all appropriate measures to ensure that children of working parents have the right to benefit from childcare services and facilities for which they are eligible.

The Committee on the Rights of the Child in its General Comment No. 7:

'Implementing Child Rights in Early Childhood calls on Government to ensure that all young children (and those with primary responsibility for their well-being) are guaranteed access to appropriate and effective services, including programmes of health, care and education specifically designed to promote their well-being. Particular attention should be paid to the most vulnerable groups of young children and to those who are at risk of discrimination (art. 2). This includes amongst other groups children with disabilities. (para 9)

## Theme 2: Support at Key Stages

This theme looks at the experiences and needs of disabled children at key times and stages of their life:

- Early identification and intervention
- Access to early years' services
- Transition services and support

### Early identification and intervention

#### Issue:

Disability may occur for many varied reasons at any point in a child or young person's life. However, for children and young people with disabilities and their parents/carers assessment processes can be lengthy and may result in little or no intervention. There are growing concerns that, with increasing levels of need, tightening eligibility criteria and reduced budgets, this situation will worsen over the period 2011-2015. Parents complain of having to manage multiple appointments and, at times, receiving conflicting advice. Professional efforts are not usually co-ordinated between disciplines. Services are often linked to diagnosis, so children without a diagnosis can lose out even if they clearly have complex needs.

#### What is needed:

Whatever the age of the child/young person early identification and appropriate follow up intervention is essential. Government and its agencies must adopt a joint approach to early intervention which ensures and facilitates access to relevant, co-ordinated support, learning, care and treatment services. It is essential that the range of professionals working with disabled children and young people have the knowledge, awareness and training to support the early identification process and make appropriate referrals to more specialist services as necessary. Early intervention programmes introduced into Northern Ireland must be accessible, appropriate and inclusive of disabled children and young people and their families. Demonstration of their impact must include evidence of their effectiveness and relevance to the needs and circumstances of disabled children and their families.

## Did you know?

Understanding the Needs Of Children In Northern Ireland (UNOCINI) is the standard model of assessment used in children's services in Northern Ireland. It is an integrated approach to the holistic assessment of a child and their family's needs targeting resources at those families who are identified as in need or at risk.<sup>44</sup> CLIC Sargent (2009) has recommended that to deliver quality care for children with cancer early assessment, care planning and a key-worker role, is essential in order to improve outcomes for children and young people.<sup>45</sup>

The Children and Young People's Strategic Partnership has decided that a shared key strategic objective is to focus efforts on early intervention. The Health Social Care Board (HSCB) and the Public Health Authority (PHA) Commissioning Plan<sup>46</sup> states that the Board's commissioning decisions in relation to children and young people will be consistent with this strategic objective on early intervention.

## Children's rights context:

UNCRC General Comment No. 9 (2006) The Rights of Children with Disabilities states:

"Very often, disabilities are detected quite late in the child's life, which deprives him or her of effective treatment and rehabilitation. Early identification requires high awareness among health professionals, parents, teachers as well as other professionals working with children...

"...The Committee recommends that State parties establish systems of early identification and early intervention as part of their health services... links should be established between early intervention services, pre-schools and schools to facilitate the smooth transition of the child." (para 56)

Article 25 of UNCRPD states persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. This article also states that health services should be provided including early identification and intervention as appropriate and service designed to minimize and prevent further disabilities.

## Access to early years' services

### Issue:

The early years are a critical period for disabled children. Their development is affected by the support and services they receive during these years. Universal early years' services are not always accessible to children with disabilities.

### What is needed:

Additional support so that children with disabilities and their families have equal opportunity to benefit from the universal early years' and family support programmes that are available to their peers and, where appropriate, access to specialist support and interventions.

The Early Years Strategy must promote a cohesive cross Government approach, which is inclusive of the specific needs and circumstances of children with disabilities and their families in these important early years.

DE must ensure the inclusion of specific actions and targets within the strategy which reflect the diversity of needs and the different processes and professionals involved in the assessment, diagnosis and care of disabled children in the early years. For some disabled children this may be from birth or before they start school. Parents of disabled children may need specific information and support to reduce the isolation and exclusion they experience. Extra support may also be needed by disabled parents, including parents with a learning disability, to support them in their parenting role.

Greater collaboration and joint working within and between agencies and professionals involved in early years, pre-school and disability is required to maximise access and benefit to disabled children and a sharing of knowledge and expertise across education, health and social care.

### Children's rights context:

UN Committee on the Rights of the Child General Comment No 7 (2005) 'Implementing child rights in early childhood': The Committee identified children with disabilities as one of the groups of young children in need of special protection.

“Early childhood is the period during which disabilities are usually identified, and the impact on children’s well-being and development recognised... A priority is to ensure that they have equal opportunity to participate fully in education and community life, including removal of disabling barriers that impede realisation of their rights... Young disabled children are entitled to appropriate specialist assistance, including support to their parents (or other caregivers).” (para 31 d)

## Transition services and support

This section looks at the experiences of disabled children when:

- Leaving hospital
- Leaving school
- Becoming more independent

Disabled children experience a number of key transitions within their lives: from hospital to home, from primary to secondary education, from school to further education, training and employment, as well as the transition to adult health and social services and ultimately to becoming an independent adult.

Often young people and their parents/carers experience “cliff edges” in service provision, particularly in relation to the transition to adult health and social care services. Young people and their families can experience delays as they undergo re-assessments to check their eligibility for health and social care services, including AHP (Allied Health Professional) services. Young people with less severe disabilities, such as those with mild or moderate learning disability, may find that, despite their need for extra support, they do not meet the criteria for accessing services or support.

In addition, there is no agreed standard age used to determine the upper age at which young people are able to access children’s services. For example children may transfer to adult wards in acute hospitals at 14; they may transfer from community children’s nursing between 16 and 18 years and they may no longer qualify for children’s respite services at 16 years of age.

There is a need for a standard, agreed upper age limit that young people can access childrens’ services before moving into adult services.

Effective support needs to remain available for all disabled children and young people throughout the various transitions in their lives.

Currently the support that children and young people receive is variable in terms of the preparation and planning for their transition. Children and young people are not routinely involved in decisions that affect their lives.

Transition from school can be a time of stress for children, young people, parents and carers. It is essential that children, young people and parents are involved, informed at all stages of the transitional process and recognised as a key partner in the process.

There is also an absence of age appropriate, accessible and real options across the entire range of transition phases.

### **Did you know:**

Disabled young people may wait up to 26 weeks from referral to commencement of Allied Health Professional services when entering adult services.

From April 2010, the HSC Board and Trusts should ensure no patient waits longer than 9 weeks from referral to commencement of Allied Health Professional services.<sup>47</sup>

## **Leaving hospital**

### **Issue:**

Disabled children and children with complex physical health care needs often spend longer in hospital than necessary, where they are more vulnerable to infection and isolation.

Parents and carers described their children becoming institutionalised as a result of their prolonged hospitalisation which may impact on social and emotional development.<sup>48</sup>

Once ready for discharge delays continue due to the lack of community services to support parents and families, particularly Community Children's Nurses, delays in establishing funding for care packages at home and availability of equipment.

### What is needed:

Implementation of McConkey et al's (2008)<sup>49</sup> recommendations in relation to effective discharge planning for children with complex needs transferring from hospital including a specific service framework for families and children with complex physical care needs; an assessment tool to be used by health and social care, education, voluntary organisations to determine and review needs; an identified key worker to co-ordinate service inputs; an audit by HSC Trusts of nursing services for children with complex needs; training for staff on specific procedures; review of the arrangements for the commissioning and delivery of equipment; the need for more respite/short breaks provision for children with complex healthcare needs as well as joint planning on funding arrangements with the Department of Education for health care posts in schools.

### Did you know?

Ventilated children stayed up to 7 to 18 months longer than necessary in hospital.<sup>50</sup>

The Health and Social Care Review<sup>51</sup> 'Compton Review' has proposed close working between hospital and community paediatricians through Integrated Care Partnerships.

## Leaving school

### Issue:

Young people with disabilities are faced with limited choices in the transition from school in comparison to their non-disabled peers. Young people living in rural areas may have fewer post school options and a lack of accessible public transport which further reduces choice.

### What is needed:

There is an urgent need for an interdepartmental approach to transitional planning, with the development of a commonly agreed operating model of delivery with shared values and principles across all sectors for all disabled children providing a clear and consistent pathway for all.

A multi-agency transition service for disabled young people aged 14-25 is required in every area to ensure person centred support at this critical time. Each disabled

young person should have access to the information and advice they need and a range of real options to enable them to reach their potential and look forward to their future with confidence. This support should encompass the needs of the whole child and not just the educational output; and enhance their connections with local activities, facilities and services, increasing their involvement and inclusion in the life of their local community.

### **Did you know?**

Until 2008/2009, the Department of Education School Leaver's Survey only recorded the number of pupils leaving school with special educational needs in mainstream education.

In 2007, in response to the Report of The Transitions Inter-Departmental Working Group, a number of voluntary organisations across Northern Ireland involved in the provision of transition support services identified some major ongoing issues of concern within the sector around the transition of young people with disabilities from school, and outlined their view on principal elements of best practice in transition support.

The Bamford Monitoring Group<sup>52</sup> identified transition planning and post school options as a concern for parents and has made a series of recommendations including that the DHSSPS should work in collaboration with Government departments delivering the Bamford Vision action plan to identify a clear post-school pathway for people with a learning disability including all the options for education, training, work and leisure that are available.

The 'National Programme for Developing Person-Centred Approaches to Transition'<sup>53</sup> has been piloted and rolled out by the Valuing People Support Team in Great Britain since 2005.

The Children and Young People Strategic Partnership (CYPSP) has established a transition sub-group which should help various agencies develop a regional, more consistent and person-centred approach to transition.

### **Children's rights context:**

UNCRC General Comment No. 9 (2006) The rights of children with disabilities states:

“The Committee recommends that States parties continue and strengthen their efforts to take into consideration the views of children with disabilities and facilitate their participation in all matters affecting them within the evaluation, separation and placement process in out-of-home care, and during the transition process.”

Non-Discrimination - The UN Committee on the Rights of the Child (2002) noted its concern that the principle of non-discrimination is not fully implemented for all children in all parts of the State Party and that there is unequal enjoyment of economic, social, cultural, civil and political rights, including for children with disabilities. (2002 Concluding Observations para 22)

## **Becoming independent**

### **Issue:**

To be able to live independently is an aspiration for many young people including those with disabilities. Loosening strong family ties, getting jobs, managing households, developing social lives and intimate relationships and attaining a sense of oneself as an equal citizen can be more difficult for young people with disabilities. Currently there is limited co-ordinated support across agencies and a lack of tailored services to enable young disabled people to make this transition to independent living.

The lack of appropriate support and learning opportunities for young disabled people limits their opportunities to develop new skills or maintain those they learnt at school.

### **What is needed:**

A strategic co-ordinated approach which results in empowering young disabled people to become independent, confident adults is urgently needed.

This strategic approach must set targets across departments to ensure equal opportunity for young disabled people to live independently in all aspects of their life. There is a need for investment in age-appropriate accommodation, ensuring that young people with disabilities are supported to live at home or to move to alternative accommodation of their choice.



Young disabled people should have access to life and work skills training including travel training, money management, and personal safety and relationships.

### **Did you know?**

Northern Ireland has the highest proportion of people living in long stay hospitals in the UK.<sup>54</sup>

The Health and Social Care Review<sup>55</sup> 'Compton Review' has proposed that a commitment is made to closing long stay institutions and to completing the resettlement process by 2015.

### **Children's rights context:**

Article 19 of the UN Convention on the Rights of Persons with Disabilities says that people with disabilities have the right to live independently in the community. People with disabilities must have the opportunity to choose where and with whom they live and be supported in doing so.

## Theme 3: Health and Well-Being

This theme looks at what needs to be done to enhance the:

- Mental health of disabled children and young people
- Physical health of disabled children and young people
- Support provided to children with complex health needs
- Personal relationships and sexual health

### Mental health of disabled children and young people

#### Issue: Access to services and support

Disabled children and young people are at a higher risk of developing mental ill health than other children and young people and yet they continue to experience great difficulty in accessing child and adolescent mental health services.<sup>56</sup> Research on the impact of the conflict has largely ignored the impact on children and young people with disabilities.

A report by the Regulation and Quality Improvement Authority (RQIA) on child and adolescent mental health services drew attention to the continuing accommodation of young people with mental health difficulties in adult wards, despite investment in a purpose built in patient facility. The report also drew attention to the absence of policy guidance and model of service provision which means that each Trust develops services differently. The report concluded that, although there had been some improvements in the range and availability of some services such as eating disorders and crisis intervention, more needed to be done to ensure that children and young people with mental health needs can access advocacy support, be “seen by the right person at the right time in the right place” and experience a smooth transition to adult mental health services, if required.

#### Proposals on mental capacity legislation

Government proposals for mental capacity legislation<sup>57</sup> indicates that the new bill will only apply to people over 16 years and that some aspects of the legislation will not apply to young people aged 16 and 17 years.<sup>58</sup> The Government recognises,

however, that specific arrangements will need to be made for the small number of children and young people under 16 years who are currently detained under the 1986 mental health legislation so that they can come within the remit of the legislation and benefit from its safeguards. This also includes children aged under 16 who may be detained in the future under the new Bill.

It is anticipated that the statutory right to advocacy support will be provided for within the new mental capacity legislation, raising concerns about the extent to which most disabled children and young people will be able to benefit from this important right. CDSA is concerned, too, that DHSSPS, in its draft policy on developing advocacy services, focused primarily on the development of advocacy support services in anticipation of the new mental capacity legislation, failing to take adequate account of the importance and need for advocacy support to be developed for all disabled children and young people, including those under 16 years.

### **What is needed:**

More targeted, early intervention and preventative approaches to enhance the emotional health and well-being of disabled children and young people and provide support to their families. Equal access to child and adolescent mental health services for children and young people with disabilities across Northern Ireland. Children and young people should never be placed in adult facilities.

Children and young people who come within the scope of the new mental capacity legislation must be afforded the same safeguards as adults and have their rights, distinct needs and interests protected and promoted in accordance with the requirements of international human rights law.

### **Did you know?**

It is estimated that more than 20% of young people are experiencing 'significant mental health problems' by their 18th birthday.<sup>59</sup>

Deaf children and young people are 60% more likely to experience mental health problems than other children.<sup>60</sup>

Children and adolescents with a significant learning disability are 3-4 times more likely to experience mental health problems.<sup>61</sup>

The Bamford Monitoring Group asked young people for their views on the information available on HSC Trusts websites about mental health services for young people. They said that the information should be more accessible, easier to find and be written **by** and **for** young people.<sup>62</sup>

The Service Framework for Mental Health and Wellbeing<sup>63</sup> has been published and aims to improve the mental health and wellbeing of the population of Northern Ireland, reduce inequalities and improve the quality of health and social care in relation to mental health. It sets standards in relation to the prevention, assessment, diagnosis, treatment, care, rehabilitation of individuals and communities who currently have or are at greater risk of developing mental illness.

### **Children's rights context:**

In its 2008 Concluding Observations the UN Committee on the Rights of the Child (2008) expressed concern that:

“... while 1 in 10 children in the State party have a diagnosable mental health problem, only around 25% of them have access to the required treatment and care and that children may be still treated in adult psychiatric wards.” (para 56)

The Committee made specific reference to Northern Ireland on this issue, stating that:

“The Committee is also concerned that in Northern Ireland - due to the legacy of the conflict - the situation of children in this respect is particularly delicate.” (para 56)

The Committee recommended that “additional resources and improved capacities are employed to meet the needs of children with mental health problems throughout the country, with particular attention to those at greater risk, including children deprived of parental care, children affected by the conflict, those living in poverty and those in conflict with the law.” (para 57)

Article 12 of the UNCRPD (Equal recognition before the law) states that:

People with disabilities have the right to recognition as persons before the law. People with disabilities have legal capacity on an equal basis with others in all aspects of life. Countries must take appropriate measures to provide support to people with disabilities so that they can effectively exercise their legal capacity. Article 7 of the UNCRC (Children with disabilities) states that:

“States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.”

## Physical health of disabled children and young people

### Issue:

Children and young people with disabilities are likely to experience a greater incidence of health problems and difficulties in accessing primary healthcare, for example, problems with oral health, respiratory difficulties, cardiovascular problems, mobility difficulties, obesity and low weight, as well as having a reduced resistance to infections.

Children and young people are often faced with particular barriers and challenges in their efforts to be physically active and eat a healthy diet.

### What is needed:

All health and well-being strategies published at Government and agency level should set targets to address the specific needs of disabled children and young people. There is a particular need for a holistic approach to health and well-being outcomes for disabled children and young people. Therefore, genuine cross departmental working is essential to ensure that the opportunities presented through strategic initiatives on play, recreation, sports, leisure and the arts can be maximised to promote optimal health and well-being for children and young people with a disability.

### Did you know?

A Children and Young People’s Health and Well-Being Service Framework<sup>64</sup> is under development. There will be a specific focus on children with disabilities including early intervention, all inclusive ethos, multidisciplinary teams, participation, education, respite, equipment, transition and palliative care.

The Caroline Walker Trust has produced nutritional and practical guidelines for children and adults with learning disabilities.<sup>65</sup>

The Guidelines and Audit Implementation Network (GAIN) has published Guidelines on Caring for People with a Learning Disability in General Hospital Settings.<sup>66</sup> The Guidelines include a specific standard on improving the experience of children with a learning disability.

## Support provided to children with complex health needs

### Issue:

There are increasing numbers of children with complex health needs, including children who are technology dependent, or who may require 24 hour personal care and increasingly intensive nursing care. Most children are being cared for at home by their families.

Children with complex needs are more likely to experience exclusion from mainstream and support services due to perceived risks and the lack of appropriate training for staff in this area.

There is a lack of choice and opportunity of short breaks for families of children with complex needs.

Durability of funding for short breaks opportunities is an issue as this affects consistent service provision and familiarity of professionals to families.

### What is needed:

Innovative and appropriate service responses are required to ensure that children and young people with complex needs and their parents get access to the support they require throughout their life and this includes access to high quality children's palliative care services in the setting of their choosing.

A regional training strategy is required to ensure that staff are confident and competent when delivering services and support to children and young people with complex needs in their daily lives.

### Did you know?

The Compton Review of Health and Social Care<sup>67</sup> not only recognised the importance of early intervention for children with a learning disability, but also the

growing numbers of young disabled people with complex needs who are surviving into adulthood.

### **Children's rights context:**

In its 2008 Concluding Observations the UN Committee on the Rights of the Child noted its concern that children with disabilities continue to face barriers to the enjoyment of... the right to access health services and recommended that Government take all necessary measures to ensure that legislation providing protections for persons with disabilities, as well as programmes and services for children with disabilities are effectively implemented... and provide training for professional staff working with children with disabilities, such as medical, paramedical, and related personnel, teachers and social workers.

### **Personal relationships and sexual health**

Young people with a disability have the same aspirations and desires as their peers. Like other young people they have a right to develop personal relationships and express their emotions and sexuality. This is an important part of a full and equal life based on the right to independence, control and life choices. The Bamford Review (Equal Lives Report) drew attention to the increased vulnerability of children and young people with a learning disability to abuse and exploitation. It stated that the school curriculum for young people with a learning disability should encompass personal safety and personal relationship issues.

The Department of Education does not currently regulate the delivery of Relationship and Sexuality Education (RSE) in schools, therefore there is no consistency of approach across schools, with some young people not receiving adequate information to enable informed choices about their lives. There are also concerns that RSE is currently under resourced, with a lack of guidance and support for teachers who deliver the subject.<sup>68</sup> Other gaps in the delivery of RSE in schools include an absence of sexual health information available to young people in special schools.<sup>69</sup>

### **What is needed:**

The development of a comprehensive sexual health strategy, which gives particular consideration to the rights and needs of disabled children, young people and ensure equal access to information, support and services in respect of sexual and reproductive health.

Clearer guidance and training for professionals, front line staff and families so that they can advise and support young people with disabilities and their carers on sexual health matters.

Young people should get the extra support they need so that they can make positive and safe choices. They should get accessible education about relationships, sexuality and healthy choices, and about sexual health services.

### **Did you know?**

Research indicates that although people with a learning disability in Northern Ireland want to learn more about sexual health and relationships ultimately their sexual needs were being ignored.<sup>70</sup>

NICCY has recommended that the DHSSPS, as part of delivering on a comprehensive sexual health strategy, review sexual health services and information for young people with disabilities to provide support for the young person, their parents/ carers and front line professionals.

RSE co-ordinators have developed a series of quality resources, including interactive materials for pupils with special educational needs, to support the learning and teaching of more sensitive issues within the RSE programme.

The Children and Young People Health and Well-Being Service Framework will address the promotion of age appropriate sexual health.<sup>71</sup>

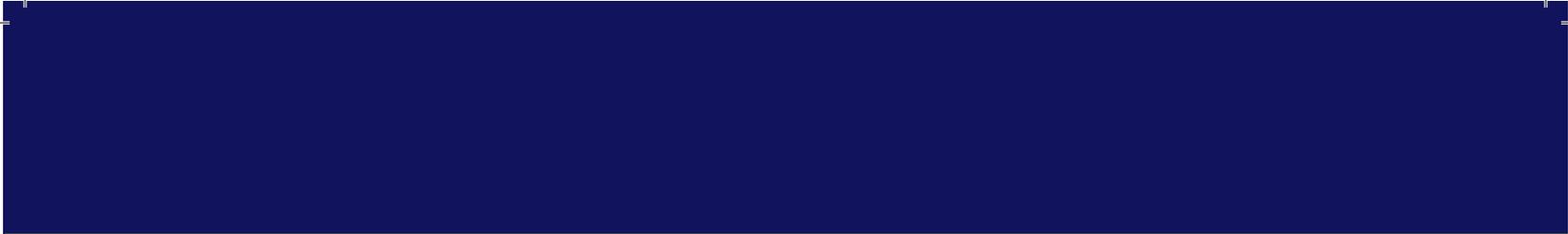
### **Children's rights context**

Article 22 (Respect for privacy of) of the UNCRPD states that:

People with disabilities have the right to privacy. Information about people with disabilities including personal information and information about their health should be protected.

Article 23 (Respect for home and the family) of the UNCRPD states that:

People with disabilities have the right to marry and to found a family. Countries must provide effective and appropriate support to people with disabilities in bringing up children, and provide alternative care to children with disabilities where the immediate family is unable to care for them.



Article 25 (Health) of the UNCRPD states that:

People with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination. Countries must take all appropriate measures, including measures that are gender-sensitive, to ensure that people with disabilities have access to the same range, quality and standard of health care that is available to everyone else, and which are close to people's own communities.

## **Theme 4: Access to and Participation in Play, Recreation, Leisure, Sport and Cultural Life**

### **Issue:**

Play and leisure opportunities available to children and young people with disabilities are limited because of difficulties associated with accessing and participating in mainstream play, leisure, cultural, arts and youth activities. Where activities are available, they are often unwelcoming and fail to make reasonable adjustments or provide the extra support that some children need to participate.

There is a heavy reliance on volunteers, or parents/carers of disabled children, to provide alternative activities, with few opportunities for parents' to develop skills to support their children in play.

In addition, there is limited monitoring by public service providers of the use and take up of services and activities by disabled children and young people.

Sport plays a key role in social integration, social inclusion and equal opportunities for children and young people with a disability. However, sometimes it can be difficult for children and young people with a disability to participate in sporting activities as they face additional barriers such as physical (i.e. environment), communication, cost, transport, attitudes or procedural issues.

### **What is needed:**

Every child with a disability should have appropriate support so that they can enjoy the same play, leisure, cultural, arts and youth activities as their peers. Providers across all sectors must demonstrate that they are genuinely inclusive of, and encourage the active participation of all disabled children and young people. Play, leisure, culture, sports and youth service providers should monitor use and uptake of these services and demonstrate that they are inclusive.

Policies for play, leisure, culture and sports should ensure children and young people with disabilities can access and benefit from mainstream opportunities. They must recognise that some children with disabilities may need targeted provision and support to participate, and this will require adequate funding. The policies should include specific indicators to monitor the use and uptake of such opportunities by children and young people with disabilities.

The Play and Leisure Implementation Plan recognises that children and young people with disabilities and additional needs are restricted from accessing play and leisure which limits opportunities for inclusion and integration. The proposal for a pilot project focused on the play and leisure needs of children with disabilities is welcome and must be taken forward as expediently as possible through engagement and consultation with disabled children and young people and parents/carers.<sup>72</sup>

### **Did you know?**

The Department of Culture, Arts and Leisure (DCAL) Sports Matters Strategy<sup>73</sup> aims to deliver an increase of 6% in the number of people with a disability who regularly participate in sport and physical recreation by 2017.

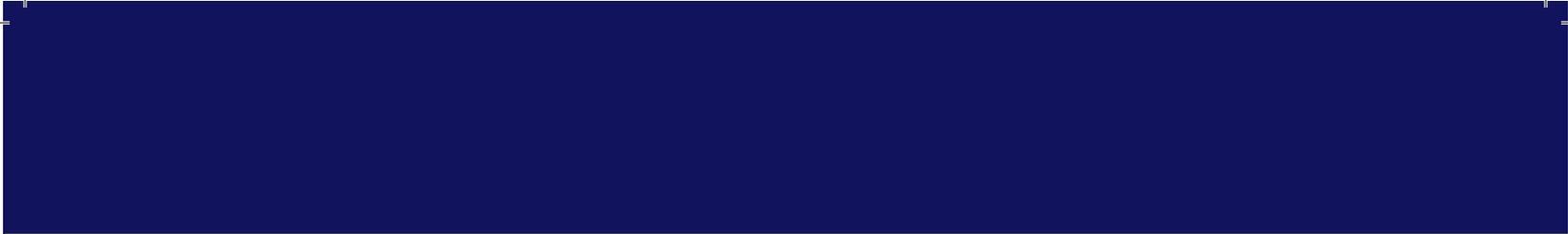
Research carried out by Contact a Family pointed to a high level of social exclusion amongst disabled children and young people across the UK, in accessing play and leisure activities. A staggering 73% of families indicated that they are going without leisure/days out due to a lack of money. For families with disabled children, leisure/days out can result in additional cost, for example they may require a care worker or may need to drive everywhere to transport their child's equipment, so incur care or petrol costs when they go out.<sup>74</sup>

### **Children's rights context:**

In its Concluding Observations (2008), the Committee on the Rights of the Child expressed concern that children with disabilities continue to face barriers in the enjoyment of the right... to access leisure and play (para 52) and further the Committee noted that with the sole exception of Wales, the right to play and leisure is not fully enjoyed by all children in the (UK), especially due to poor play infrastructures, notably for those children with disabilities." (para 68)

The Committee on the Rights of the Child, in its concluding observations (2008), recommended that the UK "should pay particular attention to provide children, including those with disabilities, with adequate and accessible playground spaces to exercise their play and leisure activities." (para 69)

Article 30 of the UN Convention on the Rights of Persons with Disabilities (2006) specifies the right of people with disabilities, including children and young people, to participate in cultural life, recreation and sport. In particular, that children with disabilities have equal access to participation in play, recreation, leisure and sporting activities, including those activities in the school system.



UNCRC General Comment No. 9 (2006) The Rights of Children with Disabilities states:

“Play has been recognized as the best source of learning various skills, including social skills. The attainment of full inclusion of children with disabilities in the society is realised when children are given the opportunity, places and time to play with each other (children with disabilities and no disabilities).”

## Theme 5: Poverty and Welfare Reform

### Poverty

#### Issue:

Disabled children and young people, particularly those from families with low incomes, experience disadvantage in education, health and family life. They are at greater risk of having an impoverished childhood without access to the opportunities, life experiences and chances others take for granted.

Families are more likely to face extra costs associated with aspects such as transportation; higher heating bills; home adaptations; higher food bills; increased laundry bills; higher childcare costs; and learning aids.

Due to such costs, families with disabled children are much more likely to be in poverty. In some cases, the loss of income involved with a parent having to give up work to care for the child is also an influencing factor.<sup>75</sup> Indeed, the NISALD survey highlighted that for 38% of parents/guardians of children with disabilities under the age of 15 benefits were their only source of income.<sup>76</sup> Similarly, three in five disabled children were found to be poor under the Consensual Poverty Measure.<sup>77</sup>

Child poverty in Northern Ireland is increasing. Despite the Executive's obligations to eradicate child poverty as required by the Child Poverty Act 2010, official statistics show that Northern Ireland is the only part of the UK where the level of child poverty has increased by 3% to 28% in 2009/10.<sup>78</sup> Child poverty numbers are expected to regress to 1999 levels due to the impact of budget and welfare cuts, the rise in the cost of living and unemployment.<sup>79</sup>

#### What is needed:

The decision by OFMDFM to develop a statistical evidence based outcomes framework in order to meet the obligations of the Child Poverty Act 2010 is welcome. CDSA strongly recommends that this work acknowledges that children and young people with a disability and their families are at greater risk of poverty, identifies specific targeted actions and adequate funding to lift children and young people with disabilities and their families out of poverty; and monitors the impact of all such interventions.

Poverty measurement tools should be developed to capture a more accurate picture of the extent and impact of poverty on children and young people with disabilities and their families in Northern Ireland.

### Did you know?

- 54% of respondents to a recent Contact a Family Survey stated that not having the time or money to do things that other families do makes them feel isolated.<sup>80</sup>
- A Save the Children report<sup>81</sup> in 2011 found that 12% of children living with a disabled adult are in severe poverty compared to 8% of those children who aren't living with a disabled adult.
- Parents of children with cancer are struggling to cope with the unexpected costs of travel, childcare, food and accommodation while their child has treatment, with 66% turning to borrowing to make ends meet.<sup>82</sup>

## Welfare Reform

### Issue:

Although there is support for simplifying the welfare system<sup>83</sup>, there are concerns regarding the lack of clarity on how the changes will impact on disabled children and young people and their families and fears that the changes will disproportionately affect disabled children and their families.<sup>84</sup>

For young people over 16 years there are particular concerns that this will introduce yet another complex system for young people and their families to navigate through as they move into systems and services designed for adults. For children and young people under 16 years it is not yet clear if, or when, the new Personal Independence Payment, which is to replace Disability Living Allowance (DLA), will apply. DLA helps families meet additional costs associated with their child's disability such as transport, heating and personal care costs. Proposals to extend the qualification period from 3 months to 6 months would cause particular hardship to parents of children diagnosed with a severe or lifelong disability, or a life limiting or life threatening disability.

There are also concerns that proposals for meeting childcare costs within the Universal Credit have not taken account of the higher costs faced by families of disabled children. There are concerns, too, about the impact on low income or out

of work families with disabled children if disability additions are reduced for disabled children not receiving the higher rate of the care component of DLA or who are not severely visually impaired.

### **What is needed:**

It is essential that welfare reform address the increasing, additional and ongoing financial costs families with disabled children currently face and address the barriers to work they experience. It is essential, too, that measures taken by the Executive to mitigate the impact of welfare reform changes reflect the needs and circumstances of disabled children and their families.

CDSA recommends:

- Maintaining current levels of financial support through disability additions paid in respect of a disabled child via the Universal Credit.
- Recognising the higher costs of childcare for disabled children within the current Working Tax Credit system and, in the future, in the Universal Credit (for example, by covering at least 90% of childcare costs for disabled children with an aspiration to increase this to 100% as the economy improves).
- Extending the right to request flexible working from the first day of employment for parents of disabled children.<sup>85</sup>

### **Children's rights context:**

The UN Committee on the Rights of Children General Comment No 9 (2006) 'The rights of children with disabilities' highlights the link between poverty and disability:

"Poverty is both a cause and a consequence of disability. Children with disabilities and their families have the right to an adequate standard of living, including adequate food, clothing and housing and to the continuous improvement of living conditions. The question of children with disabilities living in poverty should be addressed by allocating adequate budgetary resources as well as by ensuring access by children with disabilities to social protection and poverty reduction programmes." (para 3)

## Theme 6: Education

### This theme looks at:

- Disability and special educational needs
- Educational attainment
- Pre-school provision for disabled children
- Further Education (FE) and Higher Education (HE) provision for young people with disabilities
- Suspension and expulsion
- Alternative Education Provision (AEP)
- Transport to and from school
- Assessment and statementing of children with special educational needs
- Limited participation of children and young people in decision making
- Special Educational Needs and Disability (NI) Order (SENDO)
- Access to curriculum and examinations

### Disability and special educational needs

The terms “disability” and “special educational needs” are defined within a range of legislation and guidance. Definitions of disability are included within legislation primarily concerned with health, social care, anti-discrimination and equality matters.

Definition of special educational needs is included within legislation primarily concerned with addressing difficulties faced by children who find it harder to learn at the same pace as other children their age and/or disabled children who, because of their disability, find it difficult to use educational facilities or services in their area.

Not all disabled children have special educational needs. Not all children with special educational needs will have a disability. Since the enactment of the Special Educational Needs and Disability (NI) Order 2005, and its emphasis on mainstream education, there has been a marked increase in the number of children with disabilities in mainstream education. There are concerns at the lack of resourcing, planning, participation and support available for these children. This has resulted in pupils with disabilities being placed in mainstream education settings that are ill prepared to meet their needs.

## Did you know?

The UN Educational, Scientific and Cultural Organisation (UNESCO) has produced Policy Guidelines on Inclusion in Education.<sup>86</sup> They act as a resource for policy makers, teachers and learners, community leaders and members of civil society to improve and develop the inclusive aspect of schools and education systems.

Promotion and safeguarding of the right to inclusive education is a key area of work within the EU Disability Strategy 2010-2020.<sup>87</sup>

CDSA has also produced the “Education Manifesto: Looking to the Future for Special Education Needs”, focusing on the future of SEN. In Northern Ireland, it proposes an inclusive special educational needs system that emphasizes the rights of children with a disability and their parents.<sup>88</sup>

## Educational attainment

### Issue:

It is crucial that schools, teachers and parents recognise the importance of encouraging the aspirations of children with disabilities. Pupils with disabilities should be encouraged to attain the best they can achieve academically, emotionally and socially.

Young people with disabilities are faced with extensive barriers in their quest for educational achievement and fulfilment. However, available data on educational outcomes is extremely limited and specific information on disabled children and young people is not consistently collected. This is particularly the case with children who have multiple disabilities. In terms of population, 44% of disabled people have no qualifications compared to 18% of people without disabilities while 12% of people with disabilities have a higher education qualification compared to 26% of people without disabilities.<sup>89</sup>

Young people with a disability have the same aspirations and goals as those without a disability in terms of education, work and independent living at age 16. However when they enter adulthood, the experiences of the two groups significantly widens.<sup>90</sup>

### **What is needed:**

There is an urgent need for Government to establish a system to collect and provide both qualitative and quantitative data on educational outcomes of children and young people with disabilities.

There is a need for appropriately resourced additional support to address the inequalities in educational attainment and low expectations so that children with disabilities and special educational needs are enabled to reach their full potential within education.

It is essential that all schools are challenged to advance the educational attainment of children with a disability. CDSA would view the proposal to investigate “Virtual schools” in the Department of Education Draft Audit of Inequalities and Action Plan<sup>91</sup> as a potentially effective means of providing critical support to schools.

### **Did you know?**

There is a significant gap in educational attainment levels between disabled children and young people and their non disabled peers. For example, 49% of deaf children in Northern Ireland get 5 GCSE's A-C in comparison with 71% of their hearing peers, equating to a 22.8% gap.<sup>92</sup>

Substantial movement with regard to the collection of statistics in Great Britain came by way of the Special Educational Needs (Information) Act 2008<sup>93</sup> which resulted in the collection and publication of a wide range of relevant educational statistics.

### **Children's rights context:**

With regard to educational attainment the UN Committee on the Rights of the Child in its 2002 Concluding Observations noted its concern at: “... the sharp differences in educational outcomes for children including children with disabilities.”

## **Pre-school provision for children with disabilities**

### **Issue:**

Access to early years' provision for young children with disabilities is limited. There is some concern regarding the capacity of some pre-school programmes to make provision for children with special educational needs. Children attending pre-school

programmes do not always have additional provision such as classroom assistants. Choosing appropriate pre-school provision is made increasingly difficult due to delays in diagnosis and assessment.

### **What is needed:**

Intervention clearly requires input of resources at the earliest possible point in time, when barriers to equality and difficulties with access to the curriculum are identified. Failure to intervene early to support pre-school children with disabilities creates barriers to inclusion which often become more difficult to overcome as time goes on and the learning gap with non-disabled peers widens.

In light of very significant, increasing levels of budget cuts to the aggregated schools budget and the direct impact upon the resources available to schools, as well as increasing constraints upon resources for specialist services provided by ELBs, it is of critical importance that specific measures are taken to prioritise, monitor and uphold the legal obligation contained in UNCRPD which the Government has accepted, to provide an inclusive education and the fullest possible educational and social integration for children with disabilities.

Children with disabilities should have equal access to appropriate and quality early years' provision. Early intervention to remove barriers to equality of access to education is critical if the right to education is to be upheld for children with disabilities. There needs to be a reduction in diagnostic and assessment waiting times so that children with disabilities are able to access the most appropriate provision.

To deliver inclusive provision staff in pre-school settings must have access to good quality training and guidance alongside appropriate access to external specialist support to enhance their capacity to meet the needs of all disabled children. It is vital that families are provided with good quality information and support during this time especially on promoting communication, play and social relationships.

### **Did you know?**

The Department of Education is piloting Early Intervention Teams in each of the five Education and Library Board areas. It is essential that these pilots are determined, developed and implemented with regard to robust evidence of the particular needs of disabled children. It is crucial from the outset that pilots are developed in close collaboration with key professionals from health and social care, as well as parents/ carers.

A SEN resource file for early years settings is being developed.

### **Children's rights context:**

The UN Committee on the Rights of the Child General Comment No 9 (2006) The Rights of Children with Disabilities states:

“Early childhood education provided by the State, the community, or civil society institutions can provide important assistance to the well-being and development of all children with disabilities.” (para 65)

Government is obliged to ensure that children with disabilities have access to their human rights (including education) on an equal basis to other children, under Article 7 of the UNCRC. In Article 24 of the UNCRC, which recognises the right of persons with disabilities to education, it is provided that “States Parties shall ensure an inclusive education system at all levels. . . .”

In particular, under the UNCRC, it is clear that legal obligations towards children with a disability extend to education in the widest sense to ensure that they can attain full inclusion, participation and integration within the general education system (which under a UK Reservation to the UNCRC includes both mainstream and special education) and within society in a manner which enables children to reach their full potential.

### **Further Education and Higher Education provision for young people with disabilities**

More and more young people are staying on in post-16 education as a wider range of vocational and academic courses become available and, along with various funding mechanisms, act as an incentive for young people to stay on in education. FE colleges are required to have regard to the needs of students over compulsory school age who have learning difficulties (FE (NI) Order 1997).

#### **Issue:**

The numbers of students with disabilities entering Higher Education (HE) or Further Education (FE) is increasing.

SENDO promotes inclusive education and requires universities/colleges not to discriminate against disabled students, to assess their needs and to seek to make reasonable adjustments to enable them to access their education. Students should not be at a disadvantage because of their disability either in accessing a course or in the assessment process.

The transition to university or college is more likely to be successful if a student has had good transition experiences in the past. It is important that there is good communication between children and adult health and social care teams involved with disabled young people who are moving toward HE/FE. Knowledge about the young person's needs has to be shared with those professionals that will be assisting the move to HE/FE.

A Bamford Monitoring Group report showed that going to college was an important step towards independence and employment for most people with a learning disability. The report drew attention to the limited range of courses available for people with a learning disability, which resulted in some students repeating courses, and the lack of choice for many students in which course they attend.<sup>94</sup>

Government must address the distinct needs and circumstances of children and young people with a disability who may disengage from the education system at an early age.

Despite evidence that young people with a disability are identified as a group that are likely to be most associated with 'not being in education, employment and training' (NEETs) and even though they are likely to be in the NEET category for longer than their peers<sup>95</sup>, there is no clear, disaggregated data or information on children and young people with a disability who are considered to be NEET.

The proposal to focus on 16-19 year olds who are not in education, employment or training disadvantages disabled young people who leave school after 19 years, even though they are likely to face similar barriers to accessing employment and training when they leave school and come within the NEET category.

Greater attention needs to be paid to the barriers and difficulties faced by all young disabled people and the extra support they need to become or remain engaged, included in, and able to access opportunities in education, employment and training.

An overriding focus on narrow age bands and categories can militate against the proper identification of those children and young people with a disability that need extra support to remain engaged and included within the education system.

## What is needed:

Better information, help and support to young people with disabilities and their families to make informed decisions in making the transition from school, including decisions to go into FE / HE.

Improvements in the tracking and monitoring of the numbers of disabled young people who find themselves NEET across the age categories.

There is a need for greater understanding and appreciation of the transition process, the different circumstances and needs of disabled children and young people, the range of educational settings they attend and the different ages that they leave school, which if not carefully planned and prepared for, with full involvement of the child and young person, can result in them being excluded from interventions designed to address the needs of young people who are not in education, employment or training.

Ongoing commitment is required of all the agencies involved in facilitating or supporting the transition process to engage with and progress the recommendations made by the Transitions Sub Group of the Children and Young People's Strategic Partnership.

Implementation of the recommendations made by the Bamford Monitoring Group to improve FE provision for people with a learning disability including liaison between Departments, particularly the DEL, DHSSPS and DE, to ensure better transition planning; clear pathways to help young people progress from school, to college to employment; enhancement and protection of the courses available to people with a learning disability on preparation for work, independent living, and leisure; and more involvement of young people with a learning disability in choosing courses and subjects.<sup>96</sup>

Continued implementation of the recommendations made by the Education and Training Inspectorate (ETI) for DEL and providers in its report on provision for people with special educational needs or disabilities in FE. This includes the need for multi-agency working across organisations, ensuring that learners with special educational needs or disabilities are able to access the information and guidance they need; continued work with DHSSPS to ensure that provision complements that provided by day care, as well as improved information, support, and training for providers to help them respond effectively to the additional complex needs of learners as well as improved access to Information and Learning Technology (ILT) and Assistive Technology.<sup>97</sup>

The implementation of the 'Higher Education Strategy for Widening Participation' must include targeted initiatives and support to increase the numbers and proportion of disabled students accessing HE.<sup>98</sup>

### **Did you know?**

Following their Inquiry into NEETs, the Employment and Learning Committee<sup>99</sup> recommended "work is undertaken to better track and monitor the numbers of disabled young people who find themselves NEET. This should allow for better provision for disabled NEET young people to be incorporated into the NEET strategy (Para.78)."

## **Suspension and expulsion**

### **Issue:**

In 2004, a DE consultation on change to suspension and expulsion procedures proposed that pupils with a statement of Special Educational Needs (SEN) should not be expelled from school.<sup>100</sup> However, a significant number of children with statements of SEN are suspended or expelled from school. These pupils can find it particularly difficult to obtain alternative education.

### **What is needed:**

Current education policy on suspensions and expulsions must be reviewed with separate guidance in relation to special educational needs. Pupils with challenging behaviours rather than face suspension or expulsion should have a statutory assessment or reassessment as part of an educational needs review before action is taken. Their needs could be re-assessed and more support and guidance on managing challenging behaviour provided to schools to give greater understanding of needs.

### **Did you know?**

The most recently available statistics show that during the course of the five years to 2008/2009, 223 pupils were expelled, of which 89 (almost 40%) were at Stages 1-5 of the SEN Code of Practice. In 2008/09 there were 36 expulsions, with 22 of these pupils (61%) on the SEN Code of Practice.<sup>101</sup>

### **Children's rights context:**

With regard to suspension and expulsion the UN Committee on the Rights of the Child in its 2002 Concluding Observations noted its concern “at the still high rate of temporary and permanent exclusion from school affecting disabled children amongst other groups of children”.

The Committee recommended that Government “undertake all necessary measures to remove the inequalities in exclusion rates between children from different groups”. (para 45-46)

## **Alternative Education Provision (AEP)**

### **Issue:**

A significant proportion of children in AEP have special educational needs but some programmes do not have the capacity or expertise to make provision accessible for these children.

### **What is needed:**

The ETI<sup>102</sup> recommended earlier identification of children's problems and the need for more preventative work in primary schools, including support for children with special needs.

Where children with special educational needs do access AEP there is a need for proper, stable, long-term funding for these projects and access to resources ranging from standard educational psychology or welfare services right through to physical resources such as Information and Communications Technology (ICT) equipment, art, science and Physical Education (PE). Robust information sharing procedures must be put in place to ensure projects have full and accurate referral information relating to the young person. Teaching staff must be able to access professional development courses that recognise the diverse special educational needs of the young people accessing these projects. Post 16 support services must be developed for those leaving these projects.

## Did you know?

In 2010/11 21 (55.3%) primary school children accessing EOTAS<sup>103</sup> provision were at stages 1-5 of the SEN Code of Practice and 338 (74%) post primary school children accessing EOTAS provision were at stages 1-5 of the SEN Code of Practice.<sup>104</sup>

## Transport to and from school

### Issue:

Children travelling to special schools considered their journey as being too long. Transport methods, including public transport, while meeting minimum requirements, may not always be fully accessible for children with disabilities. There are also concerns relating to child safety in private hire taxis and buses where securing wheelchairs can be problematic. Access to after school activities may be limited due to the inflexibility of transport.

School transport is specifically excluded from the decision-making powers of the Special Educational Needs and Disability Tribunal (SENDIST) even though transport is often an unresolved issue for children with special educational needs and disabilities who need a package of assistance in order to attend school and access the curriculum. Granting of support for SEN and disability is not conducted by the same division of Education and Library Boards that grant home to school transport. The transport division do not have access to reports about the child unless the parent pursues transport and provides the information. Transport is treated as a “non-educational need”. Parents are generally unaware of how they can challenge a decision relating to transport.

### What is needed:

Flexible, appropriate, fully accessible school transport is essential to support the positive inclusion of children with disabilities in school life. There is a need for specific research to focus on the transport needs of children with disabilities.

The SENDIST should have an extension of its powers to allow disputes about transport to be resolved in light of full information about all of the child’s needs. In any event, parents should be given a specific right to appeal a decision about

provision of transport as well as information about how to appeal a transport decision.

## Assessment and statementing of children with special educational needs

There are 5 stages to the current process for the identification and assessment of special educational needs and provision:<sup>105</sup>

- **Stage 1:** teachers identify and register a child's special educational needs and consulting the school's SEN co-ordinator, take initial action.
- **Stage 2:** the SEN co-ordinator takes lead responsibility for collecting and recording information and for co-ordinating the child's special educational provision, working with the child's teachers.
- **Stage 3:** teachers and the SEN co-ordinator are supported by specialists from outside the school.
- **Stage 4:** the Board considers the need for a statutory assessment and, if appropriate, makes a multi-disciplinary assessment.
- **Stage 5:** the Board considers the need for a statement of special educational needs; if appropriate, it makes a statement, arranges, monitors and reviews provision.

### Issue:

A delay in assessing need has a significant impact on a child's educational experience and may leave schools struggling to provide adequately for a child's needs. Inadequate numbers of educational psychologists coupled with a lack of statutory time limits in relation to the school based stages of the process, in particular Stage 3, has resulted in unacceptable waiting lists regionally.

At present there is only a statutory time frame for Stage 4 assessment and Stage 5 (statement issued). Delays in reports being forwarded by non-educational services can mean that, despite statutory time limits, these are not always adhered to. Difficulties arise when the quantity and type of support provision such as speech and language therapy and occupational therapy is not made explicit within Part 3 of a statement. The Department of Education's Code of Practice on the Identification and

Assessment of Special Educational Needs (1998) states in relation to Part 3 Special Educational Provision that ‘provision set out in this subsection should normally be specified, detailed and quantified’.

The Department of Education’s Policy Proposals for the Way Forward for Special Educational Needs and Inclusion<sup>106</sup> proposes a new framework which has emerged following a DE review of the current system. However, there are fears that the proposals will lead to greater uncertainty, reduce further the confidence of parents, and fail to effectively address the shortcomings of the current system, eroding the existing entitlement of children with disabilities to special educational needs provision. The Department of Education is proceeding with the reform of the SEN framework and eventual legislative change. To address ongoing concerns it is crucial that the Department ensure regular and ongoing engagement and appropriate consultation with stakeholders, particularly parents and children and young people, as policy and legislation develops.

### **What is needed:**

There is an urgent need to address the current obstacles to effective Special Educational Needs provision. A review must be undertaken with regard to the number of educational psychologists available and a strategy developed to reduce and respond appropriately to the current numbers on the waiting list for assessment.

The Department of Education’s Early Intervention Teams pilots in part have been created to address this issue. This does not however meet the needs of those children at Stage 3 of the Code of Practice who require an educational psychologist’s assessment in order to receive the appropriate special educational needs provision.

There must be an effective, co-ordinated approach between education and health and social care trusts to plan, deliver and meet distinct needs of children with special educational needs in all educational settings. This includes access to occupational therapy, speech and language therapy and other support services such as Information Technology (IT) and transport. Joint training is essential.

When drafting the current statement of SEN, or any future similar statutory document, it is essential to specify and quantify appropriate levels of provision including access to additional support services before the final statement or statutory document is issued. A statutory time frame should be introduced to require the ELBs/ Education and Skills Authority (ESA) to discharge its duty to identify the children who

may need assessment and statementing.

Legislation relating to special educational needs should include provision that in the exercising of all duties and functions the overriding principle guiding the ELBs/ESA should be the best interests of the child.

Changes (amendments) to the current system of responding to the needs of children with SEN must result in greater parental confidence in the process and ensure the child's right to special educational needs provision is protected, strengthened and enforceable. There should be no erosion of the statutory rights of appeal to SENDIST.

### **Did you know?**

The most recently available statistics show that delays experienced in the process range from 41 days (Belfast Education and Library Board) up to 136 days and 196 days if only school age (South Eastern Education and Library Board) for Stage 3 and 4. Latest figures show that over 1800 children in Northern Ireland are currently awaiting special needs assessment.<sup>107</sup>

These figures only relate to the length of time children young people with special educational needs and disabilities are waiting for an Educational Psychologist's assessment at Stage 3 and 4. There are additional delays to the process due to budget constraints on schools which influence the number of children at Stage 3 that schools can refer to the Educational Psychologist in a school year. This results in children having to wait until the next school year before a referral can be made to assess their needs. Budgetary conditions mean only four or five children a year from a school can be put forward for an Education Psychologist's assessment.<sup>108</sup>

### **Children Right's Context**

Article 3 of the UNCRC states, 'In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.'

## Limited participation of children and young people in decision making in education settings

### Issue:

Although guidance in the Code of Practice on SEN recommends that children and young people's views are sought and taken into account when decisions are being made, children with special educational needs do not have a legal right to make an appeal to the SENDIST.<sup>109</sup>

Representation and advocacy services for children with SEN and for their parents have no legislative basis and are not funded by the DE. Although legal aid is available through a solicitor to obtain independent expert evidence to support an appeal, there is no legal aid funding for representation. Given the complexity of the law on SEN and the level of legal regulation of hearings at Special Educational Needs and Disability Tribunal (SENDIST), a lack of continuity in case planning via funding for legal representation for children and their parents is a major barrier to children's equality of access to their educational rights.

The regional inter-board Dispute Avoidance and Resolution Service (DARS) is currently under-used by the public. There are concerns that the primary reason is public perception that this service is not fully independent from the Education and Library Boards.

### What is needed:

Disabled children must be empowered and supported to give their views and have them given due weight in all matters concerning their education. In particular, there is a need for fully resourced independent advocacy and representation services for children with special education needs. A legislative right of appeal to the SENDIST must be granted, supported by a publicly funded legal aid.

Awareness raising is required to promote and encourage use of the regional DARS.

### Did you know?

Young people with disabilities consider that the lack of respect for their views was 'poisoning' their school days (Educable, 2000).

The Equality Commission Conciliation Service has been established in law under the provisions of the SENDO to deal with disputes involving claims of disability discrimination in education.<sup>110</sup>

The Assembly Committee for Education is holding an Inquiry into School Councils. The aim of the Inquiry is to champion and celebrate the work of School Councils in Northern Ireland. It will examine the experience, operation and contribution of school councils in Northern Ireland, with a view to identifying ways to support and enhance their work.

It is essential that the Inquiry gives particular attention to how effectively schools councils have listened and responded to the experiences of children and young people with a disability and/or SEN within the context of international obligations contained in both the UNCRC and UNCRPD.<sup>111</sup>

### **Children's rights context:**

The UN Committee on the Rights of the Child, in its 2008 Concluding Observations expressed concern that there had been little progress to enshrine article 12 in education law and policy. In particular, the Committee remarked that “insufficient action has been taken to ensure the rights enshrined in article 12 to children with disabilities.” (para 32)

Furthermore, the Committee went on to note its concern that “participation of children in all aspects of schooling is inadequate, since children have very few consultation rights; in particular they have no right to appeal their exclusion or to appeal the decisions of a special educational needs tribunal.”

The Committee recommended that Government “ensure that children who are able to express their view have the right... to appeal to the special educational need tribunals.” (para 67)

Article 7 of the UN Convention on the Rights of Persons with Disabilities states that:

“States Parties shall ensure that children with disabilities have the right to express their views on all matters affecting them.”

## Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO)

### Issue:

Currently, school based funding for SEN is not ring-fenced for disability provision. This allows money that would otherwise be spent to improve the education of disabled children can be spent on other school projects.

Lack of training for teachers and classroom assistants, as well as lack of appropriate resource materials to support pupils with disabilities in mainstream education, has been highlighted by organisations working with disabled children and young people.<sup>112</sup>

Specialist provision from Education and Library Boards is insufficient to meet demand so that schools are left ill-equipped to ensure equal access to education for children with disabilities. The result is that provision for children is often resource based rather than needs based.

Disabled children and their families should have the same choices as others in their community as to which school they attend.

The SENDIST deals with disputes about special educational provision and deals with allegations of disability discrimination against schools and/or ELBs. There are issues around access to justice and parity of arms for disabled children and their parents/carers as legal aid is not available for representation at hearing (although expert reports may be financed from the legal aid fund).

Disability law is well known to be a very complex area of the law, as is education law. Education and Library Boards bring a Solicitor and often instruct Counsel to attend a SENDIST process. They tend to bring their own expert witnesses (e.g. therapists, psychologists) to the hearing along with Education and Library Board Officers. A self-representing parent simply will not have the tools to deal with such a scenario on an equal basis. Many parents from vulnerable or disadvantaged groups would not even consider exercising their right of appeal in such an environment.

The lack of parity of arms is compounded by the fact that, unlike the situation in England and Wales, parents or their representatives have no access to case reports from previous cases. However, Education and Library Boards have access to these

as respondents to the applications. Since family law cases are anonymised and reported on the Court Service website, it seems there is no rationale for this lack of fairness and transparency in SENDIST cases

### **What is needed:**

Funding for SEN should be ring-fenced and schools / Education and Library Board's / Education and Skills Authority held responsible.

A major training programme for teaching staff in mainstream on SENDO and inclusion needs to be on-going for professional development and to meet the diverse needs of the children and young people with special educational needs.

Investment needs to be recurrent to address any skills and knowledge gaps within learning communities in relation to SENDO, a particular disability, learning disability, or need. There is a need to increase the level of outreach/support services available to schools and teachers.

Increased recognition should also be given to the expertise and knowledge of special school staff and the advantages that are associated with utilising their experience to advise and support mainstream staff. In addition, there is also a need to increase the number of specialist staff across all sectors and ensure that every school has access to appropriate specialist knowledge or expertise.

There is a need for legal aid funding to be extended to cover representation in SENDIST cases and for case reporting to commence so that the system is fairer and more transparent for users.

### **Did you know?**

The DE Resource file on SEN<sup>113</sup> attempts to collate the most recent and pertinent information the Government has regarding SEN best practice most notably the legislative framework, SENDO (2005). The resource file is a welcome development from the 2009 policy framework "Every School a Good School".<sup>113</sup>

### **Children's rights context:**

UNCRPD Article 24. 2(a) states that people with disabilities should not be excluded from the general education system on the basis of disability. Moreover, that people with disabilities are able to access an inclusive and quality primary and secondary

education on an equal basis with others in the communities in which they live. In addition, UNCRPD Article 24. 3(c) states that action should be taken to ensure that education, and in particular education for children who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximise academic and social development.

## Access to curriculum and examinations

### Issue:

Ongoing efforts are being made to ensure the curriculum and examinations are accessible to all children. Awarding bodies have a statutory duty to eliminate discrimination and design examinations to ensure all components are accessible to all learners - including disabled candidates. They must demonstrate no possible alternative of assessment before resorting to exemptions.

In cases where exemptions are required, enhancements will ensure that disabled students, unable to access any part of the examination, will have their marks enhanced to reflect their performance on the part of the examination completed. Certificate indications do not constitute a 'reasonable adjustment' and serve only to stigmatise candidates in future employment and education.

### What is needed:

An equitable, fair and robust system of examinations and qualifications, which enables disabled learners to obtain qualifications, to compete with non-disabled peers and obtain access to FE, HE and employment on an equal basis.

The provision of guidance and materials for teachers to enable them to meet the individual learning needs of each child. This must be accompanied by appropriate training and awareness for teachers in relation to the diversity of special education needs.

### Did you know?

Council for the Curriculum, Examinations and Assessment (CCEA) is in the process of developing guidance and materials to assist teachers in adapting the curriculum for children with disabilities.<sup>115</sup>

RNIB found that in schools, only 27.6% of English set texts are available in large print at Key Stage 4 while only 37.9% are available in Braille. At Key Stage 3, only 2.3% of Maths textbooks are available in large print while 14% were available in Braille.<sup>116</sup>

In July 2009, DE carried out a pre consultation on Guidance on accessibility requirements for Schools and School Authorities under SENDO 2005. The DE guidance provided

- Advice to public authorities responsible for schools about statutory requirements for their Accessibility Strategy, which informs the School Accessibility Plan (SAP) at a strategic level; and
- Advice to schools about the School Accessibility Plan – the statutory requirement for planning and making improvement to access to the curriculum, information provided in the school, and the school’s physical environment for pupils with SEN/D.

### **Children’s rights context:**

Article 24 of the UNCRPD states that children with disabilities should receive the support required to facilitate their learning and development.

This article also states that teachers, including teachers with disabilities who are qualified in sign language and/or Braille should be employed and that professionals and staff who work at all levels of education should receive training. This training “shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.”

## Theme 7: Protection from Abuse

### Issue:

Disabled children are particularly vulnerable to all forms of abuse. Contributory factors include physical vulnerability, communication difficulties, denial and lack of respect for their human rights.

Disabled children are more likely to be abused than non disabled children. Research would suggest that disabled children are three times more vulnerable to sexual abuse.<sup>117</sup> The presence of multiple disabilities appears to increase the risk of both abuse and neglect due to:

- Intimate care being provided by a number of different people,
- An increased reliance on residential settings for respite and difficulties in disclosing abuse when it is occurring.<sup>118</sup>

The complexities and vulnerabilities of disabled children and young people were highlighted by the Independent Review into Safe and Effective Respite Care for Young People with Disabilities at Cherry Lodge Children's Home and the Social Services Inspectorate's 'Care at its Best' report of the multi-disciplinary inspection of services for disabled children in hospital. These reviews made a series of recommendations relating to the care of disabled children.

### What is needed:

The Regional Safeguarding Board for Northern Ireland<sup>119</sup> must establish a priority focus on children and young people with a disability and their families. It is imperative that in terms of delivering safeguarding policies for children with disabilities that there is close collaboration and integrated working between those professionals with safeguarding expertise and those professionals with expertise on disabled children and young people.

Child protection registers should specify any disabilities that a child included on the register may have.<sup>120</sup> This would provide important information on the prevalence of child protection concerns relating to children and young people with disabilities and help inform the development of specific and targeted interventions for children with disabilities where there are safeguarding concerns.

Procedures to safeguard and protect children should reflect the needs and interests of disabled children, protect them from abuse and take action when they are abused.

Staff working in child protection should have the necessary knowledge and skills to ensure that their services are fully accessible and supportive to all disabled children.

Those working directly with disabled children need an increased awareness and knowledge of child protection and how to recognise signs of abuse when it is occurring.

Disabled children must have full and equal access to the available therapeutic interventions to aid recovery.

### **Did you know?**

During 2010/11 there were 34,447 referrals to children's social services, relating to 26,725 children. There were 801 children referred with a disability.<sup>121</sup>

The DHSSPS is working to finalise standards for disabled children in hospital and draft guidance and standards for disabled children receiving short break/respice care in children's homes and in host family situations.<sup>122</sup>

A recent report<sup>123</sup> concluded that focussing on disabled children's human and civil rights can protect children from abuse, help prevent unintended abusive practices in both residential and community settings and play a key role in carrying out effective investigations of abuse when it does occur.

NSPCC research found that both central Government and local child protection services have so far, generally failed to effectively protect disabled children from abuse.

### **Children's rights context:**

In its 2006 General Comment on the Rights of Children with Disabilities the UN Committee observed that children with disabilities are more vulnerable to all forms of abuse be it mental, physical or sexual in all settings... it is often quoted that children with disabilities are five times more likely to be victims of abuse.

The Committee urged Governments to take particular measures including:

- (a) Train and educate parents or others taking care of the child to understand the risks and signs of abuse of the child.
- (b) Ensure that parents are vigilant about choosing caregivers and facilities for their children and improve their ability to detect abuse.
- (c) Provide and encourage support groups for parents, siblings and others taking care of the child to assist them in caring for their children and coping with their disabilities.
- (d) Ensure that children and caregivers know that the child is entitled as a matter of right to be treated with dignity and respect and they have the right to complain to appropriate authorities if those rights are breached.
- (f) Ensure that institutions providing care for children with disabilities are staffed with specially trained personnel, subject to appropriate standards, regularly monitored and evaluated and have accessible and sensitive complaint mechanisms.
- (g) Establish an accessible, child sensitive complaint mechanism and a functioning monitoring system based on the Paris Principles.
- (h) Take all necessary legislative measures that are required to punish and remove perpetrators from the home ensuring that the child is not deprived of his or her family and continue to live in a safe and healthy environment.
- (i) Treatment and re-integration of victims of abuse and violence with a special focus on their overall recovery programme.

On the particular issue of sexual exploitation the Committee observed that children with disabilities are more likely than others to become victims of child prostitution and child pornography. The Committee urged Governments to ratify and implement the Optional Protocol on the sale of children, child prostitution and child pornography (OPSC) and in fulfilling their obligations to the Optional Protocol, pay particular attention to the protection of children with disabilities recognising their particular vulnerability (para 77).

Article 16 of the CRPD states that measures must be taken to protect all people with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse.

Also that State Parties shall put in place effective legislation and policies, including women and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against people with disabilities are identified, investigated and prosecuted.

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## Notes

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