



SCCYP

Scotland's Commissioner
for Children & Young People

A critical review and analysis of current research and policy relating to disabled children and young people in Scotland

**A report to Scotland's Commissioner for Children and
Young People**

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April 2012

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Foreword

In 2010 I undertook a national consultation with children and young people in Scotland and asked them to help me define my priorities as Scotland's Commissioner for Children and Young People. The 74,059 votes received resulted in four top categories, one of which was "*Help everyone to include each other, no matter how different we all are.*" My response to this is potentially wide ranging and it will initially focus on issues affecting the inclusion of disabled children and young people in society. This has subsequently become one of the strands of work in my Strategic Plan, 2012-2016.

There have been considerable efforts made at all levels of government in Scotland to include disabled children and young people and many groups and organisations continue to commit their resources, energy and passion to make inclusion a reality for every disabled child and young person. Yet we know that many disabled children and young people do not enjoy the same chances as their peers and their families report that inclusion remains an aspiration, not a reality. This is not good enough.

Disabled children and young people have rights guaranteed by international and domestic law. There are many aspects to a lack of inclusion, and they take numerous forms and guises in society, but they all have one thing in common – they violate children's rights. My responsibility is to safeguard the rights of all children in Scotland and to address any violations of those rights.

This report covers areas such as education, self-directed support, short breaks and transition to adulthood. It also draws attention to the specific barriers faced by deaf children, children with learning disabilities and those with mental health issues.

The report confirms that there is absolutely no room for complacency on how disabled children's rights are realised in Scotland. It will inform my plan of action in the area of disability and will sit alongside other research due to be published in this year and the work of the Disability Advisory Group convened to help direct the work.

I am grateful to Professor Stalker and Dr Moscardini for the report which helps me identify specific issues affecting the inclusion of disabled children and young people, and indicates key areas for improvement in the course of my Strategic Plan. I believe that this critical, informative and up to date overview of issues facing disabled children and young people will be of interest to a wide audience and particularly useful to those with a responsibility for ensuring that disabled children have equal chances in all aspects of their lives.

Tam Baillie

Scotland's Commissioner for Children and Young People

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I am especially grateful to Dr Lio Moscardini who wrote the section on Education policy and research for this report.

Kirsten Stalker

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1. Introduction

1.1 Aims of this work

The main purpose of this report¹ is to inform the work of Scotland's Commissioner for Children and Young People over the next four years, specifically in relation to disabled children and young people whom he has already identified as a priority group. The aims are:

1. To identify and review the major social research studies about disabled children and young people in Scotland published since devolution (1999), looking at issues which can be a barrier to their inclusion in society.
2. To identify gaps in current knowledge/research about barriers to social inclusion for disabled children and young people; for example, issues facing particular groups of children.
3. To identify and critique selected current Scottish Government policies, strategies and legislation aimed at disabled children and young people, looking specifically at issues which can be a barrier to their inclusion in society. Links to reserved Westminster legislation will also be highlighted.
4. To produce recommendations to the Commissioner on possible areas of work in relation to issues affecting disabled children and young people and specifically their inclusion in society, where his involvement is likely to add value and have potential to bring about significant improvement in the realisation of their rights.

1.2 Terminology and definitions

In this report the term 'disabled children' is used, consistent with the social model of disability. This model distinguishes between 'impairment', referring to loss or limited functioning, and 'disability,' meaning

The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical, [sensory or mental] impairments and thus excludes them from the mainstream of social activities (UPIAS 1976).

The social model locates disability in the social, cultural, material and attitudinal barriers which exclude people with impairments from mainstream life, rather than in individual 'deficit'. This perspective links well with the review's focus on barriers to social inclusion. At the same time, the social model has been criticised for its neglect of the implications of specific impairments, the role of personal experience and diversity issues such as class, gender and ethnicity. These aspects will be addressed in this report. Adopting the social model as a broad conceptual framework for the review means that children and young people with a wide range of impairments – all of whom are disabled by external barriers – are included, namely those

¹ This work was conducted late 2011 – early 2012

with physical, sensory, cognitive and communication impairments and mental health issues. The age range covered is primarily 0 – 19. For brevity, the term ‘disabled children’ is generally used except where referring specifically to teenagers, when ‘young people’ is used.

There are many different definitions of social inclusion. The Council for Disabled Children (2008) puts it this way:

Inclusion is a journey with a clear direction and purpose: equality of opportunity for all children and young people. CDC believes that the following factors are crucial to the development of inclusion:

- *a welcome for all disabled children, secure relationships and support for families when they need it;*
- *respect for difference and a commitment to building friendships and community to the benefit of everyone;*
- *equality of access to play, learning, leisure and all aspects of life;*
- *active participation of children and families in decision-making;*
- *a proactive approach to identifying and removing barriers;*
- *timely access to information and to people with empowering attitudes, supportive skills and expertise* (CDC 2008: 6).

For a more detailed and complex discussion of participation and social exclusion relating to children and young people, see Davis (2007).

1.3 Methods

To address the first two aims, six key social research studies of disabled children and young people in Scotland were reviewed. These were selected because they were published since 1999, give a holistic overview of disabled children’s lives from their perspectives (with the exception of one study about young people with complex multiple needs) and report significant findings with demonstrable policy and practice implications relating to social inclusion. The studies are:

- **Watson et al’s** (1999) study of everyday life as a disabled child. Participant observation was conducted in 14 schools, involving more than 300 pupils aged 11-16: 165 were then involved in qualitative interviews or focus groups
- **Connors and Stalker** (2003) on the views and experiences of disabled children. Guided one-to-one conversations took place with 26 children aged 7 – 15 on two or three occasions each. Parents and siblings were interviewed separately.
- **Philip et al** (2005) on mental and emotional well-being among 13 young people aged 13-29 with multiple complex needs. The researchers used diagnostic indicators to gauge young people’s well-being and interviewed eight family carers and eight care staff.

- **Highland Children's Forum** (2009) on the views of 30 young people of secondary school age about what makes a good life. The main inclusion criterion was that the young people had additional support needs and a statistically increased risk of developing mental health issues; this included a few Looked After children who were not disabled. Young people chose to respond to questions through photography, writing, drawing or interview.
- **LTCAS's** (2010) 'Seen and Not Heard?' report about issues facing children living with long-term conditions. This brings together existing evidence about children and young people's experiences, digital stories with children and young people, and conference proceedings.
- **LTCAS/ fSDC-commissioned study** (2011) of disabled children and young people's views about quality of life. Ninety-one structured questionnaires were completed mostly by (but in a few cases on behalf of) children and young people aged from 5 to 18. The findings were compared with results from a European study of 20,000 children, mostly non-disabled, using the same questionnaire (KIDSCREEN) (Ravens-Sieberer et al 2005) and a Youth Link Survey of 2000 primarily non-disabled children in Scotland.

In addition, 31 voluntary organisations and 15 academic researchers were invited to send information about any relevant research they had conducted. This resulted in further documents being reviewed which are referenced as appropriate – mostly in the policy section - along with other research already known to the authors.

In terms of policy analysis, while most policy areas have some relevance to disabled children and young people, it was agreed that the review would focus on those with most relevance to social inclusion, namely Getting It Right for Every Child (GIRFEC), The National Review of Services to Disabled Children, education, short breaks, self-directed support and transition to adult services. Welfare benefit reform has also been included. Key current policy documents in these areas were critically examined to determine how far they identify and tackle barriers to social inclusion for disabled children. Informal discussions took place with six key informants in the voluntary and statutory sectors to identify 'burning issues' in policy implementation.

1.4 Structure of this report – and its limitations

The following section presents key findings from the research review while Section 3 discusses the seven policy areas identified above, along with any relevant research. Section 4 looks briefly at two groups - deaf children and those with both learning disabilities and mental health issues. Finally, Section 5 offers a summary and conclusion and suggests next steps for the Commissioner to consider.

The very short time allocated to the review (officially 12 days) has meant that some important areas, notably the Early Years framework, have not been included. Nor was it possible to include all the research which colleagues kindly sent to us.

2. Main findings from key research studies

This section presents main findings from the six key texts identified above. It is striking that findings across these studies are for the most part very similar across a range of themes.

2.1 Family

Disabled children repeatedly identify their parents, particularly their mothers, as very important to them and usually their main source of support. Those taking part in the Highland Children's Forum study describe the ideal family as 'loving and caring' although some had disrupted experiences of family life. (This sample included non-disabled Looked After children). In relation to social inclusion, in many cases parents are the child's main advocates, 'fighting' (a word frequently used by parents in this context) to secure mainstream services and 'ordinary' opportunities. However, some children perceived their parents as over protective, as described below.

2.2 Friendship

Common to all the studies is the importance of friendship to disabled children, as to all young people. While some children report having friends, name particular friends and talk about shared fun and activities, a major theme running through the studies is that of *not* having friends or wanting to have more friends. Between a third and a quarter of the 91 children in the fSDC/ LTCAS study said that, in the previous week, they had not spent any time with friends, had fun with friends or felt able to rely on friends. These children were much less involved in social interactions than the European comparison group of 20,000. It is not uncommon for disabled children to lose touch with friends from a mainstream primary school when they move to a special secondary. Pupils attending special schools often find it hard to see their friends outside school hours because these schools have large catchment areas and the children may not be able – or allowed – to travel independently. They also report having few friends in their own neighbourhood, perhaps partly because they are seen as 'different' in not attending the local school.

Another barrier identified by some young people is restrictions set down by their parents which they sometimes consider unfair. Some want more autonomy. For instance, one child was not allowed to visit a friend because it would mean crossing a busy road, another was not allowed to go on a 'sleepover' because her diabetic treatment regime might be put at risk and a third was not allowed to go out at night with his non-disabled friends. Young people in Watson et al's study said they felt more capable than adults gave them credit for. There is some evidence of children resisting adult (parents' and teachers') views of their relative incapacity and need for

protection although little indication that they achieved greater independence as a result.

Some disabled children and those with long-term conditions would like to meet up with others who have similar experiences: more specialist support is needed to facilitate this. Watson et al (1999) found that where peer relationships with non-disabled young people were encouraged by adults, these were sometimes based on assumptions about need and care rather than equal friendship (for example, non-disabled young people assisting disabled children in play schemes as part of the Duke of Edinburgh's Award Scheme). Watson et al also found that some disabled young people were 'well in' with their peer group but suggest this was because they had been able to minimise their impairments or even 'pass' as non-disabled due to invisible impairments.

2.3 Romantic and sexual relationships

Little or no attention is paid in these studies to young people's romantic or sexual relationships. However, in a participatory action study conducted by SHS Trust (2002) with 12 young people with learning disabilities about to leave school, three said they had a boy- or girl-friend. One young woman reported that none of the significant adults in her life had recognised her relationship with her boyfriend which had ended when she left school to go to college because there was no support for them to continue meeting. Overall, these young people had little knowledge of issues relating to sex, such as consent or contraception, which raises concern about personal safety issues. They would have liked to know more but felt they should not ask because they associated sexuality with 'naughtiness'. Elsewhere, parents report feeling worried about finding appropriate ways to talk to their older disabled sons and daughters about sex and relationship issues (LTCAS 2010).

2.4 Social and leisure activities

Although public bodies have a statutory duty to make information, premises and facilities accessible to disabled children (and bearing in mind that some of this research was conducted prior to the implementation of the Disability Discrimination Act 2005), the studies report that many children experienced difficulty accessing mainstream social and recreational opportunities.

Several studies list children's favourite activities, all age and/or gender typical. As they grow older, young people generally prefer less 'organised' activities such as shopping, parties, clubs and holidays but youth-centred settings, such as fast food outlets, were not always accessible to these young people. For instance, one boy wanted to visit a local shopping mall with his friends but found that the Shopmobility Scheme only provided wheelchairs for adults. A related problem reported by parents was long waits and delays for essential equipment, especially wheelchairs: sometimes the child had outgrown a chair before it arrived. This restricted the scope for social

outings and activities. A related problem for some was lack of accessible transport to get to and from social activities, especially but not only in rural areas where social activities could be thin on the ground.

A lot of children were keen to play sports, with 'keeping fit and having exercise' identified as part of 'a good life' for any young person (Highland Children's Forum 2009). However, sports clubs and activities, especially football, were often inaccessible. For example, a boy attending a special unit at a mainstream school was not included in the main school's sporting activities, despite being a talented footballer (Watson et al 1999); elsewhere, there were no teams for children with physical impairments and no sign language interpretation for a child who was a member of a football team (Connors and Stalker 2003). These examples illustrate a range of barriers at work – discriminatory attitudes, inaccessible mainstream activities and inadequate support for communication.

Parents in one study thought that formal services did not do enough to foster independent social lives for their children and reduce social isolation. Some children needed help to socialise in clubs – 37% of the fSDC/ LTCAS respondents wanted more help to take part in activities they enjoyed - but again, this was not always available. Lack of support with communication can be a barrier to making friends. It is worth mentioning here that parents sometimes reported their child did not get enough speech and language therapy, even when it was part of his/her plan.

Another factor reported by young people in two studies was not having enough money, or less money than non-disabled children, to pursue the social activities they wanted to do: this may be related to relative poverty among families with disabled children (discussed later).

Lack of accessible social and leisure opportunities means that some children spend a good deal of time feeling bored at home with nothing much to do. Some only go out with their parents and then to places geared to adults' social needs, with few other children present (Watson et al 1999). Sometimes parents accompany children on social outings with their friends but as they grow older, this is less acceptable to the young people. Some young people have said they would prefer a person of their own age or someone who is not a family relative to support them with activities. For some, contacts outside the family are limited to volunteer befrienders, 'respite' carers or paid workers in similar roles. Support workers can get in the way of children making natural social contacts and developing peer friendships, with some young people finding that 'too much help can be stifling' (LTCAS 2010). A number of studies note that disabled children are subject to significantly higher levels of adult surveillance than their non-disabled counterparts. Some children (and their parents) are critical of Special Needs Assistants at school. Connors and Stalker (2003) report that one SNA treated a teenage boy in an inappropriately childish fashion, singing songs and kissing him, much to his embarrassment; another SNA persistently took an older primary

school pupil, who used a wheelchair, to the younger children's playground for 'safety' reasons, while a third SNA regularly took a boy to the nursery class at lunchtime because she was friendly with the staff there. These actions reduced rather than promoted the children's social inclusion at school, although the latter function is part of the SNA role.

2.5 Prejudice and bullying

The LTCAS (2010) report points to a widespread lack of awareness about and negative attitudes towards children who are disabled or have long-term conditions. A common theme across the studies (and prevalent in other research about disabled children) is the experience of being bullied. This takes place in a range of settings – at school, in college, in the local neighbourhood and sometimes at home (when children say their siblings are bullies). It takes a variety of forms – deliberately excluding the child from conversations or activities, name-calling, extracting money or other 'coveted' goods and sometimes physical aggression such as hitting, kicking or pushing the child about. Watson et al found that even where young people were not bullied, their awareness or fear that it could happen, presumably because they had impairments, affected their sense of self and social relationships. Some children report their dislike of being stared at in public, while parents have recounted inappropriate, patronising or hurtful comments made to or about their children by strangers. In an extreme case, a girl with learning disabilities describes what appears to have been a sustained campaign of serious harassment by adult neighbours, related to her impairment, such that the police were involved (Connors and Stalker 2003).

However, it would be wrong to portray all disabled children as helpless victims of bullying since some did not experience it and others took steps to address it. Some reported the problem to parents or teachers; others stood up to the bullies themselves while one or two said they gave as good as they got. Nevertheless, many children were clearly deeply distressed by these experiences which acted as a major barrier to their social inclusion. It is not surprising that children in the Highland study identified 'being treated with respect and understanding', being listened to and other people being 'friendly, kind and encouraging' as central to a good life.

2.6 Emotional well-being

In the fSDC/LTCAS (2011) study, 43% of respondents said that their life in the past week had been 'very' or 'extremely' enjoyable and a similar proportion had 'very often' or 'always' felt in a good mood and had fun. However, a significant percentage of children said they had felt sad, lonely or so bad that they did not want to do anything. The children in the fSDC/LTCAS study were more likely to feel sad than those in the other samples and had lower scores for psychological well-being. Although children with profound multiple impairment were not able to take a direct part in Philip et al's (2005) study, the authors highlight that these young

people also experience mental health issues, often for similar reasons to others, such as bereavement and, in addition, may be adversely affected by changes in routine, environment or staff. Barriers to accessing support for this group include staff shortages, ineffectual referral systems and parents feeling that they should not make demands on staff time.

2.7 Sameness and difference

Despite the difficulties reported above, research shows that disabled children are in most respects ‘the same as’ rather than different from their peers. They have a similar range of interests, pastimes and aspirations. They want to access the opportunities and experiences open to non-disabled children, with support as needed. They are however sometimes made to feel different in negative ways, indicating that the management of difference by those around them is crucial to children’s subjective well-being and social inclusion. Watson et al refer to the ‘institutionalisation of difference’ in mainstream schools, whereby disabled children often learnt, played and even ate in separate spaces from non-disabled pupils. Connors and Stalker report that one child asked what he had done wrong to be placed in a special unit, which suggests a lack of clear explanation and positive presentation of difference. Watson et al found that impairment was the dominant status ascribed to the young people in their study, the primary lens through which they were viewed by professionals, while other dimensions of their identity such as gender and ethnicity were often ignored. Pupils were sometimes introduced to visitors in terms of their impairment rather than by name. Similarly, two children in Connors and Stalker’s study reported that, in their special school, teachers referred to pupils as ‘the wheelchairs’ and ‘the walkers,’ one girl adding ‘I am happy being a cerebral palsy’. Here, and elsewhere, a lack of positive disabled adult role models is apparent.

In contrast, in some mainstream schools there seems to be a view that disabled children must be treated in the same way as other pupils, without allowing for the additional support some children need in order to start on a level playing field. This approach suggests a denial rather than an acknowledgment of difference, as if it could not be a positive. There are indications, in the ways some children describe their experiences at mainstream school, that inclusion policies are not always consistently thought through. It is almost as though there is a ‘stand-alone’ general principle that disabled children must be fully included wherever possible, but how this is to be achieved has not been incorporated into specific policies and procedures.

An issue arising in several studies concerns the provision of personal and medical care at school. The Administration of Medicines in Schools (Scottish Executive 2001) sets out good practice guidance designed to enable children with medical needs to participate as much as possible in mainstream education. It states that a healthcare plan should be drawn up by

parents, school and health care staff, and that where possible parents should not be expected to routinely deal with their children's medical needs at school. Nevertheless, there is evidence that this still happens. Similarly, one young girl in the fSDC/LTCAS study (2011) described how she sometimes soiled herself at school, in which case she had to tell the teacher, who told the school secretary, who rang the child's mother, who then made a fifteen minute journey to school to change her daughter's pads. This arrangement clearly compromised the girl's physical comfort and her dignity, marking her out as different from other pupils in a negative way.

Several studies report that some disabled children believed their education at special school to be less good than in mainstream: some had experience of both. They found special schools had a less academic orientation and they sat fewer exams there, and in different subjects, than they would have taken at mainstream. The fSCD/ LTCAS study (2011) found that disabled young people generally had low expectations of gaining qualifications at school, entering Further or Higher Education, getting a job or moving on to a career, especially when compared to the views of non-disabled young people.

2.8 Disabled children from black and minority ethnic (BME) communities

Little research has been conducted into the views and experiences of disabled children from BME communities in Scotland. Research on multi-agency working on race, youth and disability in Glasgow found that many agencies providing services to disabled people had limited or no contact with BME people of any age, with little targeted provision (Glasgow Anti-Racist Alliance 2010). Agencies reported widespread unmet need in BME families with disabled children, particularly in support and social opportunities, information and advice on service availability, and suitable adapted or accessible housing.

2.9 Advocacy

There are few references to independent advocacy in the research reviewed, other than to note a need for it. One study of advocacy support for children and young people in Scotland found significant gaps in provision for those who were disabled or had mental health issues (Elsley 2010). The author reported inconsistency in the type of service and the geographical coverage available to these groups, noting in particular that insufficient support was available to young people moving onto adult services. The paucity of independent advocacy for disabled children has serious implications for both their social inclusion and the wider realisation of their rights.

3. Analysis of policy areas and relevant research findings

In this section, we present analysis of seven key policy areas, and some related research, relevant to the social inclusion of disabled children and young people.

3.1 Welfare benefits reform

While there isn't room in this report to cover welfare benefit reform in detail, a short section is included because recent developments have far reaching implications for the social inclusion of disabled children and the well-being of their families.

The Welfare Reform Bill, which will reach Report Stage in the House of Lords on 11/1/12, aims to improve work incentives, simplify the benefits system and tackle administrative complexity (UK Parliament, 2011). At present, Child Tax Credit contains an additional element for families with a disabled child although approximately 180,000 families in the UK still receive premiums through Income Support (if they have been claiming continuously since April 2004). The basic payment for a disabled child, whether made through Child Tax Credit or Income Support, is £53.62 per week (2011/12 rates), based on receipt of Disability Living Allowance (DLA) for the child at any rate. An additional £21.63 is payable for a 'severely disabled' child to families in receipt of DLA at the highest rate of the care component for day and night care. The legislation will replace Child Tax Credit and Income Support with the new Universal Credit, in which the lower rate payment for a disabled child will be around £26.75 a week and the higher rate, around £77 a week, depending on their current DLA rate. This means that, for the majority of disabled children, the additional payment will be cut roughly in half (personal communication, Child Poverty Action Group Scotland, December 2011).

Nevertheless, the UK government has said that families currently receiving £53.62 for a disabled child will not be worse off when transferred to Universal Credit. An additional transitional amount will be payable so that they continue to receive the same amount: details of how this will work will appear in regulations. However, the higher amount will be frozen and may be lost when circumstances change. The campaigning coalition Every Disabled Child Matters warns that those who do not receive transitional protection will face an annual loss of income of nearly £1400. A hypothetical example is a child who has a temporary remission/improvement early in 2013 and DLA is withdrawn. Her condition then worsens, the family reclaims after October 2013, by which time they are on Universal Credit and the payment will be much less (personal communication, Child Poverty Action Group Scotland, December 2011). The official rationale behind the change is to bring children's premiums in line with adults' and the UK Government has stated that the Welfare Reform Bill will reduce child poverty for 350,000

individuals. However, this figure does not appear to take account of the impact on families with disabled children, leading Every Disabled Child Matters to call for an Equality Impact Assessment of Universal Credit.

The Bill also proposes that people currently receiving Incapacity Benefit (IB) will be transferred to the contributory form of Employment and Support Allowance (ESA). This will affect young disabled people aged 16 and over currently in receipt of IB and of course those who would have received IB on turning 16. Morris (2011) warns that underlying this change is a view of disabled people as either deserving, broadly equated with 'vulnerable', or non-deserving, broadly equated with 'malingering', ESA being designed, she contends, to reduce the number of people receiving benefits due to illness or disability. Morris argues that the impact of physical and mental health has not been adequately factored into the reforms and that the ascribed personal characteristics and 'lifestyle choices' of disabled people have more sway in current policy debates than the impact of employer discrimination and reduced job opportunities.

The new legislation will also replace DLA with Personal Independence Payments (PIPs). However, the UK Government recently announced that 16 and 17 year olds will be exempt from the change in 2013-14, and that it will not be extended to children 'without public consultation and parliamentary scrutiny' (UK Parliament, 2011). Eligibility assessment for PIPs will include the impact of medical treatments, aids and adaptations on a person's ability to take part in everyday life. Morris (2011) questions whether these will be used to declare ineligible, for example, wheelchair users on the grounds that they have already been provided with the means to overcome their mobility difficulties.

The proposed reforms have very serious implications, not least because nearly 50% of disabled children live with a disabled parent (Blackburn et al 2010), many of whom will be affected by the reforms in their own right. Economists have predicted a rise in absolute poverty by 2013 as a result of recent policy decisions (Action for Children, 2011b). When household money is tight, it is likely to be spent on basic necessities rather than activities which promote social inclusion.

Further, when public services are being cut to reduce the national deficit, vulnerable children and families will bear much of the burden (Action for Children 2011b). Due to its own reduced income, AfC is increasingly having to focus on families in crisis rather than taking a preventive approach in line with Government policy on early intervention.

Anecdotal evidence indicates that this is true of many voluntary and statutory sector services. Read et al (forthcoming 2012) state:

When all groups in the UK are taken together, the median equivalised income for a household with a disabled child is around 13 % lower than those with non-disabled children. They are more vulnerable to living with debt, social deprivation and in poor housing. Consequently, in addition to the exclusion and discrimination associated with living with impairment, many disabled children are likely to live in circumstances that have been shown negatively to affect children's development and educational achievement and to place them at risk of poor health and social exclusion (Shahtahmasebi and others 2010). Thus, the poverty that is part and parcel of their everyday lives has a significant impact on fundamental rights enshrined in both the UNCRC and the UNCRPD.

3.2 Getting It Right for Every Child (GIRFEC)

3.2.1 The GIRFEC framework – a brief overview

“Getting It Right for Every Child is the golden thread that knits together our policy objectives for children and young people” (Scottish Government 2010a:3). GIRFEC provides an overarching framework for children’s services endorsed by the Scottish Parliament in 2009. It demands a sea change at cultural, systems and practice level within all children’s services and also adult services where they interface with provision for children (Scottish Government 2008). GIRFEC aims to put children at the centre of practice, improve outcomes for them and ensure that all agencies respond appropriately to individual children’s needs and any risks they may face. It requires systems, services, planners and practitioners to work in an integrated and consistent manner, using a single planning and delivery system, cutting out duplication and as much red tape as possible.

GIRFEC identifies eight well being indicators: every child should be Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible and Included (SHANARRI). GIRFEC also aims to help realise the National Outcome that children should be successful learners, confident individuals, effective contributors and responsible citizens. It has ten core components, namely

1. *A focus on improving outcomes for children, young people and their families based on a shared understanding of well-being*
2. *A common approach to gaining consent and to sharing information where appropriate*
3. *An integral role for children, young people and families in assessment, planning and intervention*
4. *A co-ordinated and unified approach to identifying concerns, assessing needs, agreeing actions and outcomes, based on the Well-being Indicators*

5. *Streamlined planning, assessment and decision-making processes that lead to the right help at the right time*
6. *Consistent high standards of co-operation, joint working and communication where more than one agency needs to be involved, locally and across Scotland*
7. *A Lead Professional to co-ordinate and monitor inter-agency activity where necessary*
8. *Maximising the skilled workforce within universal services to address needs and risks at the earliest possible time*
9. *A confident and competent workforce across all services for children, young people and their families*
10. *The capacity to share demographic, assessment, and planning information electronically, within and across agency boundaries, through the national eCare programme where appropriate* (Scottish Government 2010a: 10).

Where concerns arise about an individual child, a National Practice Model, common to all agencies, should be followed. Drawing on the well-being indicators, it sets out the steps practitioners should follow to identify and address difficulties. The emphasis is on early intervention, resolving problems in a timely and proportionate manner wherever possible. A series of Practice Briefings have been issued, each focusing on a specific aspect of GIRFEC.

3.2.2 The current place of disabled children in GIRFEC

The GIRFEC framework is intended to apply to all children. There is always a risk that inclusive policies which do not highlight and take account of the particular needs of disabled children may inadvertently exclude them: as already noted, these children will often need additional support to achieve a level playing field with others and to benefit from mainstream services and opportunities. Disabled children have, until now, been relatively invisible within GIRFEC. The Scottish Government Policy Lead for disabled children was not brought into the GIRFEC team until 2009, suggesting that disabled children initially lay outwith GIRFEC thinking. There are limited references to disabled children in GIRFEC policy documents and Practice Briefings. There are also discussion points where implications for disabled children could have been mentioned but are missing. For example, the Included well being indicator is defined as children “having help to overcome social, educational, physical and economic inequalities and being accepted as part of the community in which they live and learn” (Scottish Government 2010b:4). The focus on recognising and overcoming barriers to inclusion is to be welcomed but a link to policy papers about this indicator (Scottish Government, 2010a: 14) does not provide any reference to how it applies to disabled children.

Where they are mentioned, disabled children tend to be framed in terms of individual vulnerability. For example, Practice Briefing 5 (Scottish Government 2010c) cites disabled children as an example of those with characteristics which may threaten or challenge healthy development whereas, in Briefing 4 (Scottish Government 2010d), a discussion of factors leading to children being socially excluded refers to racial and cultural discrimination but not disability discrimination. This document also identifies factors which may exclude children from their local communities but does not draw attention to material or social barriers affecting those who are disabled. Briefing 2 (Scottish Government 2010e) helpfully highlights the need to find out why any disabled child is finding an impairment more disabling than it need be but, in a later discussion on transition to adulthood, does not refer to the social, systemic and structural difficulties which often beset disabled young people at this time.

As noted above, the importance of seeking children's views is a recurring theme in GIRFEC but the fact that some disabled children, particularly those with learning disabilities, autism or communication impairments or who are deaf, may need support to communicate is not highlighted. Research in England suggests that some staff may assume that disabled children do not have views of their own or that their opinions will concur with their parents' (Morris 1999) but this is not always so (eg: Ravens-Sieberer et 2005). Many practitioners lack experience and confidence in communicating with disabled children (Stalker et al 2010). GIRFEC guidance states that practitioners should be encouraged to identify any skills gaps they may have and be given opportunities to address these. In order to seek disabled children's views and engage them fully in decision making, many workers would benefit from training in both disability equality and communication skills.

The main step towards linking disabled children to GIRFEC at national level is the National Review of Services to Disabled Children (2011a), discussed below. The Review report places policy and practice relating to disabled children firmly in the GIRFEC framework and argues that GIRFEC principles must be applied to the many complex problems besetting services for disabled children identified in the report. Interestingly, it states the need for a 'more systematic plan of action to enable the necessary changes to systems, practice and culture' (p.6) if the SHANNARI well being indicators are to be delivered for disabled children. It does not however suggest what such a plan might look like. For example, what does 'healthy' mean for a child with a life limiting medical condition and how would he be supported to achieve it? What does 'achieving' mean for a child with complex multiple impairments and how would she be supported to achieve it?

The Review Action Plan sets the task of developing a GIRFEC Practice Briefing specific to disabled children. The GIRFEC Programme Board has identified five core components as initial priorities - implementing the role of the Named Person, implementing the role of the Lead Professional,

managing concerns and risks appropriately, using the National Practice Model for assessment and planning, and promoting the single planning process for organisations to sign up and use. ‘Running through all of these’ is the importance of hearing the child’s voice². Consideration is being given as to whether the National Practice Model is suitable for use with disabled children as it stands or may need some additional tools. On the one hand, it is essential to see the child as a child first and disabled second and thus, undesirable to have separate - different - procedures for disabled children. On the other hand, there is concern that some children, for example those with complex health needs, may fall through a net within universal approaches. At the time of writing, a decision has not been made as to whether a Practice Briefing specific to disabled children should be written or whether the development of additional tools to enhance existing components of GIRFEC would be sufficient and preferable.

3.2.3 The GIRFEC Highland Pathfinder Project

Given that the inclusion of disabled children within GIRFEC policy is still at an early stage, it is not surprising that no specific research has been carried out on this topic. However, disabled children and those with mental health issues were priority groups within the Highland Pathfinder Project evaluated by Stradling et al (2009). Multi-agency strategic planning teams were set up around both groups in order to develop material for Highland’s Integrated Children’s Services Plan. Rather worryingly, at one point this research questions whether the well-being indicators should apply to all children; however, it is then usefully suggested that, for disabled children, the indicators be considered developmentally and not as measures of success or failure. Little other relevant information is provided.

3.2.4 The potential of GIRFEC for disabled children

Key Informants spoken to in this review endorsed the GIRFEC approach as eminently suitable for disabled children. While it is outwith the scope of this report to review research relating to parents’ experiences of trying to secure support for their disabled children, numerous studies over the last several decades have recorded their ‘struggle/ fight’ to secure adequate services. Reported problems include a lack of information about what is available and how to access it, little or no co-ordination between agencies, the child’s or family’s needs having to fit into ‘the system’ rather than a person-centred approach which puts the child first, and the absence of a single named person acting as a central co-ordinating point. Burns’ internal report for the Scottish Government (2009), based on extensive consultation with parents across Scotland, sets out these and similar problems.

A number of studies in the UK have shown the positive benefits of key workers, care co-ordinators or local area co-ordinators when these are

² As noted in the GIRFEC Highland Pathfinder work

available to families with disabled children. Therefore, if the GIRFEC approach were to be thoroughly and effectively implemented for families with disabled children – a process likely to take some years given the entrenched problems already existing and the transformation not only in activity but in attitude and orientation which GIRFEC demands - then it would be hugely welcomed by families with disabled children. Indeed, it would resolve most of the problems they have long complained of.

3.3 The National Review of Services for Disabled Children in Scotland

3.3.1 Introduction

The impetus to hold a national review of services to disabled children sprang from a commitment made in the Scottish Parliament in March 2010, during a debate on the Public Services Reform Bill. The review was to start in May and deliver a report to Parliament by Christmas 2010. There were three main partners - the Scottish Government, COSLA and fSDC - plus a steering group comprising 24 local authority, health services, voluntary sector and academic representatives. The group was (and is) ably chaired by Harriet Dempster, former Director of Social Work Services for the Highland Council. Its aim was to “assess the current state of services for disabled children in order to begin the process of real change” (Scottish Government, 2011a:1).

Delays in agreeing terms of reference meant that the group did not meet and work did not begin until September 2010. Thus the real time scale for the review was very short, with implications for its ability to consult with disabled children. A report and action plan was completed by Christmas although publication was delayed until February to give COSLA time to seek approval from its members. The steering group was reconvened, with some changes in membership, in August 2011 for a further seven months, with a remit to “provide direction, and oversight to the Scottish Government and partners in the implementation of the actions and principles in the National Review of Services for Disabled Children” (Scottish Government 2011b). At this point, the Chair made consulting with disabled children a priority, setting up a working group to take this forward with the aim of seeking children’s views about aspects of the action plan and any missing items important to children. This work is on-going at the time of writing.

3.3.2 The Review report

Poor baseline data

The report runs to 28 pages of text followed by an action plan. It begins with an examination of definitions and numbers of disabled children in Scotland, highlighting the fact that an exact figure is not known. This relates to differing definitions of disability, poor recording of impairment and

inconsistent data collection, plus the fact that different data sets span differing conditions and age groups.

To address the problem, Scottish Government funded the fSDC Liaison Project to bring together, publish a report and set up a database of information about disabled children already in the public domain. An immediate aim was to provide baseline data for the review itself with a longer term aspiration that local authorities, health boards and others would submit both missing and new information, thus enabling the database to be regularly updated. In the event, however, *Setting the Scene* (fSDC 2010) served to highlight but not fill the gaps in knowledge, very few agencies submitted fresh data and the Scottish Government only funded one update of the database. However, more accurate data will emerge from the 2011 census which collected more detailed information about disability than in previous years, and from local authorities which, under the Education (Additional Support for Learning) (Scotland) Act 2009, must collect data about the numbers of children with additional support needs and the reasons why support is required.

The context of service delivery

The review report sets out the complex context in which support to disabled children is delivered, highlighting the GIRFEC framework, as discussed above. It acknowledges the many difficulties reported by parents seeking support for their children.

A significant contextual feature is the relationship between Scottish Government and local authorities post-Concordat, described in the report as one of 'partnership and local flexibility'. Whatever the other advantages of the Concordat, it is hard to see the benefits for disabled children, given the current unevenness of provision across the country, acknowledged in the report, plus the fact that £34 million given to Holyrood by Westminster in 2007 for services to disabled children could not be ring-fenced when passed on to local authorities. The actual sum spent on services for disabled children subsequently proved almost impossible to identify, despite a high profile campaign attempting to do so run by the fSDC Coalition, leading to a widespread view that only a fraction of the sum was spent on improving support for this group. This situation suggests a need to ensure funding and support for disabled children are well embedded and ear-marked within the Children's Services Bill which the Scottish Government intends to bring forward in 2013.

Another issue worth mentioning, with particular relevance to the social inclusion of disabled children, is the association noted in the report between disability, poor health, poverty and inequality, an interaction which can only be increased by the current Welfare Reform Bill³, as discussed earlier.

³ Information correct at the time of writing

Problems and gaps in provision

The review identifies a number of critical issues and gaps in provision. These can be summed up in the three areas identified by the Social Work Inspection Agency (2010) as ripe for improvement in services to disabled children, namely empowerment in decision-making and accessing resources, responsive services and timely support, and improving the quality of services.

More specific issues identified, some of which are discussed elsewhere in this report, include:

- Insufficient short breaks
- Low take-up of Direct Payments
- Insufficient support provided until a family reaches crisis point
- Involvement of multiple agencies but no-one has an overall co-ordinating role
- Balance between risks and rights often being settled in ways that limit children's inclusion
- Poor medical support for pupils at school
- Transition points, particularly to adult services
- Neglect of the social and educational needs of disabled children who are Looked After and those spending prolonged periods in hospital.

Conclusions and Action Plan

Not surprisingly, the report concludes that, despite some advances in recent years, there is a long way to go before national priorities set out under GIRFEC will be realised for disabled children, and better outcomes delivered. A long list of areas for improvement includes, at the top, paying better attention to children's views. Service planners and providers need to:
...tap in more systematically, and in a more varied range of ways, to the way young people view the routes they take through life and the barriers they have to face or envisage (p.20).

Also of interest to this review for Scotland's Commissioner for Children and Young People are: mainstream services must offer equal access to everyone, the costs of inclusion should be an integral part of service planning, and the need for stronger capacity building in mainstream organisations to welcome disabled children. The Action Plan sets out a range of tasks and identifies in broad terms which bodies are responsible for progressing each.

When the steering group reconvened in August 2011, an updated action plan was circulated and is now reviewed on a six weekly basis. Most of the actions from this plan are currently being taken forward by the Scottish Government in collaboration with relevant agencies. Areas where there has been little or no movement are: piloting the fSDC Charter for Disabled Children, which local authorities have been unwilling or unable to take on; and reinforcing the importance of local authorities regularly reviewing

Children's Integrated Services Plans (an action for COSLA). Actions where progress is at an early stage are the inclusion of children's disability issues within the national Child Poverty Strategy and within housing support. This does however mean that headway is being made on the 11 other tasks identified in the report, progress in some cases being significant, for example in relation to short breaks, as discussed below.

Disabled children who are looked after

Following the report of the National Residential Child Care Initiative (2009), a Looked After Children Strategic Service Implementation Group (LACSIG) was set up in October 2011, tasked with addressing widespread delays in making permanency decisions and finding adoptive parents for Looked After children. A sub-group is focusing on disabled Looked After children because they appear to wait longer than average for permanency and have a higher turnover of placements. The Group's first task is to obtain better statistics about the numbers of Looked After disabled children and then to encourage better forward planning, with a view to encouraging more foster carers to adopt the disabled children placed with them.

3.4 Education

3.4.1 Introduction

In education the most significant piece of legislation in the new millennium relating to additional support needs was the Education (Additional Support for Learning) Scotland Act 2004, amended in 2009. This legislation displaced the term 'special educational needs' and set in place the broader and more inclusive concept of 'additional support needs' (ASN). This broader concept is consistent with a social model of disability. The related Code of Practice revised in 2010 (Scottish Government, 2010f) outlined the following four factors that may give rise to additional support needs:

- the learning environment;
- family circumstances;
- social and emotional factors;
- disability or health need.

Disabled children and young people are recognised within the broader group of children and young people with additional support needs.

The national Statistical Bulletins on pupils and schools in Scotland published annually by the Scottish Government show consistently that the largest group of children and young people with additional support needs are those identified as learning disabled. However, the bulletins state that 'there are wide variations in the extent to which pupils with disabilities had been identified in different local authorities and the information should not be considered as complete'. This has been a long-standing problem, with the Riddell Committee stating in 1999 that there were 'no precise figures

available on the number of children likely to meet a definition of severe low-incidence disabilities'. Guidance on census completion given to local authorities by Scottish Government in the School/Pupil Census Data Specification Uplift 2011 document lacks clarity. This may go some way to explain the discrepancy across local authorities on the number of children identified as learning disabled, including those within special schools. HMIE have recommended that Scottish Government and education authorities should ensure effective collection and management of data so that children can receive the support they need (HMIE, 2010). Scotexed documentation shows that in 2010 the number of pupils recorded as 'assessed disabled' decreased by 44%; there was an increase in three local authorities but a decrease of more than 50% in 16 local authorities.

The Doran Review Committee is currently carrying out a strategic review of learning provision for children and young people with complex additional support needs and will report in Spring 2012. The interim report (Doran, 2011) recognised the lack of consensus around the definition of complex needs and concluded that there was a need for reliable data collection for strategic planning. Keil et al. (2006) maintain that a lack of clarity around definition can lead to the marginalisation of disabled children. The importance of clarity to support a focussed response is evident when one considers the following alarming statistic: the 2009 Statistical Bulletin shows that the exclusion rate of pupils with additional support needs is almost five times greater than for pupils who do not have additional support needs; within this ASN group the number of pupils who are 'assessed or declared disabled' is almost double that of those not 'assessed or declared disabled'.

3.4.2 Provision

There is a range of provision of special schools and units across local authorities with a few local authorities having no special schools. The 'presumption of mainstream' as set out in Section 15 of the Standards in Scotland's Schools etc Act 2000 took effect in 2003. This has not led to a significant reduction in the number of children placed in special schools but there has been a change in the characteristics of special school populations which is not solely linked to a policy of inclusion (Head and Pirrie, 2007). A survey of children's views on inclusion, accessibility and additional support (Children in Scotland, 2007) found that the inclusion of pupils who required additional support was of benefit to all pupils; there were issues of accessibility and pupils viewed this as a fundamental aspect of inclusion. Pupils recognised that as well as physical adaptations, curricular and pedagogical adaptations are required.

A larger study, (Woolfson et al 2007), found that disabled pupils were generally satisfied with access to information but wanted more consultation about access to the curriculum. Curricular issues are particularly significant for learning disabled pupils and connect with longstanding concerns about teachers' professional development and whether different pedagogical

knowledge is required for the inclusion of some learners. Riddell et al (2006) outline the two differing schools of thought on this: one maintains that most children can be taught through generic approaches; the other, often argued by voluntary organisations and campaigning groups, maintains that specific approaches are required for particular types of impairment. This is a complex issue recognised in the literature as dilemmatic. Studies by Pirrie et al (2006) and Simmons and Bayliss (2007) identify this as a professional development issue across sectors. HMIE's 2009 report on Scottish education outlined the need to 'identify and tackle barriers to learning before they become entrenched [and] to find new ways to meet the needs of the increasingly diverse population of learners'.

3.4.3 Additional support beyond the school

Under the 2004 ASfL Act, 'additional support' related to school based support. The 2009 amendments extend this requirement beyond the school to include other agencies. The articulation of ASfL policies and procedures with GIRFEC reflects this amendment. A European study by Zijlstra and Vlaskamp (2005) showed that for children with profound learning disabilities who require hospitalisation due to medical conditions, there is a risk that educational support is put on hold. Recent HMIE inspections of hospital and out of school services in three local authorities were generally satisfactory but there were recommendations to develop the curriculum and to extend the implementation of co-ordinated support plans.

3.4.4 Frameworks for support

Staged Intervention (SI) is the framework for support set out in the Code of Practice (Scottish Government, 2010f) and recommended for all local authorities. It sits within the framework of GIRFEC. SI requires appropriate planning to be in place. Depending on the level of support required, this may be within regular group planning but for many disabled children this will require an individualised education programme (IEP). The process of staged intervention, including the various levels of individualised planning, is set out and labelled differently across the 32 local authorities. Regardless of the particular model of SI in place, the highest tariff of individual support plan relevant to all local authorities is the Co-ordinated Support Plan (CSP) which is the only statutory plan and was intended to replace the Record of Needs. However, through their SI frameworks many local authorities have put in place high level multi-agency support plans that are not statutory, referred to in some local authorities as ASP4s. Authorities may be using ASPs to avoid being bound to the statutory responsibilities which come with CSPs: only 0.5 per cent of the state school population now have CSPs. Most children in special schools who previously held Records of Need under the old system now have ASPs.

HMIE have called for greater consistency in the provision of CSPs (HMIE, 2010). Scottish Government statistics for 2010 show that the highest

recording authority has ten times more CSPs opened than the lowest recording authority. Dr Mike Gibson, the former head of Support for Learning Division, Scottish Government has stated that ‘we are in a worse position with CSPs than we were with records of needs’, expressing a concern that education authorities may not be fulfilling their statutory duties, in which case it falls to the parents and young people to ensure that effective provision is in place (Gibson, 2011). This concern relates particularly to children who require co-ordinated support to be in place. It is consistent with the stance taken by the Doran Review team who stated that complex additional support needs should not be interpreted as ‘referring solely to the needs of children with multiple physical, sensory and intellectual impairments’ (Doran, 2011, p.7); complex additional support needs can arise from any of the four factors outlined in the Code of Practice and can refer to the complexity of support arrangements required. While education authorities may argue that higher tariff but non-statutory planning recognises this, it does little to assuage parental concerns about provision and may ultimately result in a reference being made to the Additional Support Needs Tribunals (ASNTS).

A related concern, described by Riddell and Weedon (2010), is that it may be only those parents and young people who have the capacity to make representation to ASNTS or who are represented by a lobbying group, who proceed to contest provision. The ASNTS (2011) annual report shows that the largest number of references (37% of all references) related to children with autism. Learning disabled children were amongst the smallest groups represented at 6%, yet the latter is the largest group of children with ASN.

3.4.5 Curriculum

The most common adaptation required by disabled pupils concerns the curriculum; three times as many as those that require physical adaptation and twice as many that require communication adaption. Curriculum for Excellence (CfE) has replaced the 5-14 curriculum and the 5-14 Support for Learning materials which had been in place since the early 1990s. CfE is seen as an inclusive curriculum for all children. The Scottish Government Disability Equality Scheme Annual Report 2009 states: ‘The transformational change being achieved through Curriculum for Excellence which is central to Scottish educational policy will benefit all children in Scotland including those with disabilities’.

CfE has significantly broader bands of attainment than 5-14 which it replaced. Even with 5-14, teachers were concerned about tracking the learning particularly of pupils with learning disabilities. This was one of the reasons behind the development of the ‘elaborated curriculum’ which set out small steps in learning and teaching of pupils with significant learning disabilities. However, the elaborated curriculum is fundamentally a behaviourist approach to instruction that does not sit comfortably with the underpinning philosophy of CfE intended to replace it. CfE provides an

opportunity for all learners to be actively engaged in their learning and to learn with understanding.

However, there is a danger that for disabled pupils CfE will simply be mapped onto existing practice with no real change taking place. While the language used in the experiences and outcomes of CfE portends to place the child at the centre through the use of the first person (Priestley and Humes 2010), it is very likely that the technical nature of the language used would not be meaningful to learning disabled pupils. Furthermore, research evidence suggests that for disabled pupils there is a need for greater collaboration and consultation in educational planning. Teachers have expressed a significant concern with progression in CfE (Menter and Hulme, 2009). This report also recognised the tension that exists between an attainment raising agenda and drives towards inclusion.

CfE content in the Health and Wellbeing Experiences and Outcomes contains no specific reference to educating non-disabled children about disability. There is mention of the awareness of the needs and feelings of others within the context of the co-operation and competition strand of physical education. It is difficult to find information on the Education Scotland (Learning Teaching Scotland) website related to CfE for disabled children, particularly those with more complex needs and/or severe learning difficulties. The website provides information for practitioners on the following specific additional support needs: Attention deficit disorder; Autism spectrum disorders; Deaf and hearing impaired; Dyslexia; English as an additional language; Highly able children; Looked after children; Visual impairment. There is a link to the National Framework for Inclusion developed by STEC which contains professional development activities.

There is a need to explore equality of opportunity for disabled children to access all areas of the curriculum. A study carried out in 21 primary schools investigating opportunities for children with additional support needs to learn a musical instrument found that no children with a physical impairment or with severe learning difficulties received instrumental lessons (Moscardini et al 2011).

3.4.6 Initial teacher education and Continuing Professional Development (CPD)

The need for teacher professional development in the area of additional support needs has been a recurring theme over time. It was a recommendation of the Riddell Committee (1999) which also extended to support staff working with disabled pupils. There is evidence that effective inclusion is dependent on teachers' pedagogical knowledge (Riddell et al., 2006). However, many teachers believe that they are not capable of teaching all children (Florian and Rouse 2009). Professional development is also required by teachers in special schools who are similarly dealing with a changing pupil population. A study by Simmons and Bayliss (2007) found that teachers in special schools struggled particularly with pupils with

profound and multiple difficulties: the researchers encountered a ‘distinct lack of understanding of profound and multiple difficulties’ that was attributable to a lack of appropriate training.

Under the Requirements for Teachers (Scotland) Regulations 2005, teachers working with pupils with visual impairment, hearing impairment or dual-sensory impairment are required to have an additional qualification. There is no legal requirement for an additional qualification for teachers working with any other pupils with additional support needs. The *Standard for Full Registration* set out by the General Teaching Council for Scotland (GTCS) specifies that teachers must effectively identify and respond appropriately to pupils who require additional support. There is also a requirement under the *Standard for Initial Teacher Education* that programmes of initial teacher education (ITE) should prepare student teachers to support all pupils. All Scottish ITE institutions offer post-qualifying courses in the area of inclusive education/educational support. This is within the context of teachers' CPD and is recognised as such by education authorities who identify a qualification in this area as desirable.

Although universities meet the requirement that students undertaking ITE courses learn about additional support needs, there are concerns that this aspect of teacher professional development is inadequately covered at both pre-service level by universities and post-service by education authorities. In 2010 ENABLE Scotland investigated teacher professional development in the area of disability in all Scottish ITE institutions as well as across all 32 local authorities (ENABLE, 2011). ENABLE found that although all universities address additional support needs within core elements of ITE courses, the content was too basic and general. The study also reported that although most local authorities make ‘training’ available it is not mandatory. The Donaldson report also identified a need for increased teacher professional development in ASN (Donaldson, 2010).

It is noteworthy that of the six explicit references to additional support needs within the 116 page document, four are qualified by specific reference to dyslexia and autism; there is no specific mention of disability or learning disability, only ‘significant additional support needs’. Calls for further teacher development in additional support needs must be clear about the extent to which this should be general, relating to systems of support which may be embedded within ITE content, or specific, relating to particular impairments. Donaldson makes this explicit in relation to the high profile fields of dyslexia and autism. It is worth reflecting on the opportunity for teacher professional development in supporting that large group of learners who have been identified as learning disabled within the current ASN framework and who do not have powerful lobbies behind them.

Students’ written comments submitted in course evaluations of optional ASN courses at one university have highlighted the view that the content covered in these courses should be made available to all students. This concern has

been expressed consistently over a number of years. There is a practical issue around achieving a balance of all students covering essential content and recognising those areas that can be supported through post-qualification CPD. The latter professional development then becomes a matter for local authorities.

There is also a problem with teacher professional development in specific areas of disability connected to the vigorous uptake of voluntary early retirement schemes which has seen areas of expertise disappear. For example, the area of complex learning disabilities appears to be particularly poorly catered for. This was not an unforeseen problem; it has become the focus of discussion at recent STEC (Scottish Teacher Education Committee) Inclusion Group meetings. At the most recent meeting of this group, with representatives from all Scottish ITE institutions, it was agreed that the group would carry out an audit in early 2012 of the capacity to deliver in various areas of expertise and will seek collaborative ways forward. This endeavour requires the support of local authorities. There is a possibility that local authorities may look for more cost effective in-house solutions. However, the problem with such a strategy is that without a sound research base to inform professional development, all that may be achieved is a replication of current practice which research has frequently shown to be problematic.

In summary, there is a risk that recent developments in education policy in Scotland may in some respects disadvantage disabled children, especially those with complex needs. The association between children receiving as good an education as possible and their future social inclusion should not be under-estimated.

3.5 Self-directed support

3.5.1 Introduction

As Mitchell (2012) describes, an important precursor of Self-Directed Support (SDS) in Scotland was the Community Care (Direct Payments) Act 1996, implemented here in 1997, which enabled people aged 18 – 64, assessed as needing community care services, to request a cash payment instead. They could then use the money to purchase their own support either from existing service providers or by employing personal assistants (PAs). In 2001 this right was extended to 16 and 17 year olds and to the parents of disabled children, while the Community Care and Health (Scotland) Act 2002 gave local authorities a duty to provide direct payments. SDS encompasses but is wider than direct payments.

It is

... the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcomes they have agreed. SHS means giving people choice and control. The process for deciding on support through SDS is through co-production (Scottish Government, 2010g: 7).

Guidance on SDS (Scottish Executive 2007) states that it should be based on principles embedded in the social model of disability - independent living, service user choice and control, citizenship, rights, equality of opportunity and the reduction of physical, organisational and attitudinal barriers. Ridley et al (2011) claim that SDS may be the key to social inclusion for service users since it has the potential to divert thousands of people away from segregated services and into mainstream facilities and opportunities within the community. It is also a central plank within the Scottish Government's personalisation agenda.

3.5.2 Research on self-directed support

Very little research has been conducted about self-directed support for children and young people in Scotland, with two exceptions cited below.

Manthorpe et al (2011) conducted a literature review for the Scottish Government relating to barriers and facilitators of SDS. They found that published research on SDS is limited so they included work about direct payments, brokerage and personalisation. However, none of the 180 or so references cited appear specific to children.

Manthorpe et al found worryingly little evidence about the long-term effectiveness of SDS and little information about its risks, costs, outcomes, how best to monitor it or how to sustain any changes it creates. Numerous barriers are identified, perhaps the most significant being that processes and systems have not generally kept pace with the values of SDS, causing difficulties for service users, carers and practitioners. Also of potential relevance to disabled children is evidence that employing family members as PAs is not always successful. In addition, it is reported that some parents are over protective of their disabled children, reluctant to let adult sons and daughters take control.

On the more positive side, various factors can facilitate SDS including widely available and accessible information, comprehensive support for service users to think through change, availability of independent advocates, and users having pre-existing social networks. This last point is interesting in relation to SDS promoting social inclusion since it also implies that people who are more isolated may benefit less from SDS. Finally, the authors point out that none of the research they reviewed was conducted during the current economic recession which may adversely affect what SDS can achieve.

3.5.3 Scottish Government funded test sites

From January 2009 to March 2011, the Scottish Government funded SDS 'test sites' in Highland, the Borders and Glasgow. A two year evaluation of these (Ridley et al 2011) found that only 150 new SDS arrangements were set up across the three sites during their lifetime. People using SDS valued the support, flexibility and choice on offer. Benefits were reported for people with learning disabilities but those with mental health issues, or from BME

communities fared less well. The researchers found a misunderstanding among staff, users and families that SDS was an alternative to direct payments and/or direct service use. Although SDS is intended to reduce bureaucracy, paperwork actually increased, perhaps because parallel systems of SDS and direct payments were being run in tandem.

The Highland test site targeted its efforts at young people with learning disabilities in transition to adult services: 73% of its users were aged under 25, most (a figure is not given) under 18. In Dumfries and Galloway two parents of disabled children used SDS while in Glasgow nine disabled children were being assessed but had not yet received a package. Not surprisingly, then, there is little information about the effectiveness of SDS for younger children, the point being made that better knowledge of SDS within children's services and education might increase take-up by parents.

Various examples are however given of young people with learning disabilities having packages designed to increase choice, flexibility and importantly, social inclusion. For example:

Ian is a disabled teenager living in one SDS test site. At the time of the interview his SDS package had just been agreed. It was designed to pay another young person a couple of hours, twice a week to "do activities with him, keep him busy, do games, read books, do stuff together and then maybe once a month at week-ends to go out and maybe have a walk or go to the café or go to the youth centre perhaps". Also there was an option of an activity short break. Previously, the family had paid for this support themselves because DPs did not allow them to employ young people less than 16 years old (Ridley et al 2011: 62)

3.5.4 Self-directed Support: A National Strategy for Scotland

The aim of the 10-year National Strategy, launched in 2010, is to make SDS the 'mainstream approach' to the provision of social care and support for all service user groups. It "should be available to everyone but imposed on no-one" (Scottish Government 2010g: 2). The Strategy has little to say about children besides acknowledging that its main focus is on adults and that implementing SDS for children will need to build on what to date has been their limited uptake of direct payments. However, it is argued that SDS fits well with the GIRFEC aim of developing a coordinated and seamless network of support around the child. The Strategy proposes that specific work be undertaken to see how best to integrate SDS with GIRFEC, with a focus on young people moving into adult services, known to be a particular trouble spot.

3.5.5 The Social Care (Self-directed Support) (Scotland) Bill

In the summer of 2010, the Government consulted on proposals for legislation on SDS. It later issued a discussion document and draft Bill for further consultation, with a deadline of March 2011. Among other proposed

measures, the Bill, to come before Parliament in 2012, will require local authorities to offer individuals a range of support options involving different degrees of choice and control. If agreed, this will also apply to children defined as 'in need' (i.e. including disabled children) under the Children (Scotland) Act 1995. The proposed Bill also requires local authorities to empower carers to direct their support, indicating that parents of disabled children will be able to take on this role if they wish. Consultation on the Bill revealed 'overwhelming support' for the proposals on children and young people although further information was requested on how these would work. In response, the Government stated:

"We believe that 16 and 17 year olds should be able to direct their own support if they wish to do so and that younger children should have a say in the support they receive" (Scottish Government 2011c p7), adding that detailed statutory guidance will be provided.

There are some potentially tricky issues here. Which services are designed to support parents and which, children? How can a balance be struck between parents' and children's choices where these do not coincide? Homer and Gilder (2008) conducted 24 case studies of SDS in Scotland, one of which included three children aged under 16 and one young person under 21, all living with the same family and each apparently using SDS. While the numbers are too small for generalisation, the authors report a significant level of parental ambivalence towards SDS in this family and others with adult sons and daughters: parents were concerned that PAs should have a clear grasp of the young people's limitations as well as their potential, and worried that their sons and daughters were undertaking risky activities.

3.5.6 Benefits and risks

In many ways, SDS – like GIRFEC – has the potential to transform parents' experiences of support in caring for their disabled children. Significantly, it also has the potential to increase children's social inclusion, by moving them away from larger segregated settings and into a range of mainstream opportunities and activities within the community. Research reported earlier in this report documents disabled children's desire to have more friends, to join in social and sporting activities and to be supported by someone near their own age or at least outwith their family. These modest aspirations should be deliverable through SDS. In addition, children's personal preferences and priorities can be met more easily when supported on a one to one basis than in a group. Successive studies of direct payments have shown that the majority of those receiving them are very satisfied.

At the same time, there may be wider risks attached to the whole scale development of SDS. First, SDS could become a smokescreen for cuts to local authority and voluntary sector services. There is concern that some authorities began to discuss personalisation while looking for financial savings (Learning Disability Alliance Scotland 2011). Reportedly, in at least one large Scottish local authority the economic value of individuals' SDS is

typically lower than the cost of their previous service package (see also Elder-Woodward 2012). Second, SDS may become professionally driven rather than user-led (Ridley et al 2011). LDAS found that some families felt rushed into accepting SDS, with little or no sense of choice or control. To prevent this, it is vital that service users, and this should include young disabled people, are strategically involved in local development. Third, it is not clear if parents and children will have a support system in the way that Centres for Inclusive Living offer support to direct payment recipients (eg: with employing PAs), considered essential by many service users. Finally, there is a view that direct payments have played a role in the undermining of public services and a shift toward the marketisation of social care (Morris 2011). Elder-Woodward (2012) argues that the State has misappropriated the language and principles of the Independent Living Movement to promote a neo-liberal agenda fronted by personalisation and SDS. While this may be more marked south of the border, there is an argument that Scotland should be proud of its record in taking collective responsibility for social welfare - and ensure it is not lost. Homer and Gilder (2008) report 'strong cultural resistance' to SDS within children's services in Scotland, with some staff concerned about quality of care and risks to vulnerable children being exposed to the largely unregulated private market which is personal assistance.

3.6 Short breaks⁴

3.6.1 Introduction

Short breaks is probably the social care service most used by disabled children and most often identified by parents as crucial. It is sometimes credited with preventing family breakdown. There is a large body of research on short breaks for disabled children, although very little of it relates to Scotland at the present time. When working well, short breaks provide opportunities for parents and siblings to relax and/ or pursue activities which may not be possible when the disabled child is at home. Ensuring that short breaks also offer children enjoyable, stimulating and inclusive experiences should be an equal priority. Parents frequently report that insufficient short breaks are available, both in terms of type of break and the amount on offer.

3.6.2 Guiding principles

A useful starting point in terms of guiding principles for short breaks for disabled children is a paper produced by the fSDC Short Breaks Task Group (2010), which aims to stimulate discussion about improving provision and achieving better outcomes for all stakeholders. It argues that the traditional focus of 'respite care' on benefits to carers may have detracted from the

⁴ This term is used in preference to 'respite' which implies that looking after disabled children is a burden

equally important gains to be made by children. Short breaks are placed within the context of 'ordinary family life and relationships', noting that time away from families allows children to expand their horizons and develop a range of skills. Breaks should be "inclusive - supporting children and young people to participate in their 'natural' peer groups and communities" (p3). The paper argues that the current narrow definition of short breaks should be broadened beyond residential or family-based services to include a range of opportunities which non-disabled children take for granted, such as youth clubs, after school clubs, sports activities and holiday play schemes. Finally, the paper argues that short breaks are a human rights issue since they offer children a chance to socialise and develop their personalities. Both the UNCRPD (2006) and the UNCRC (1989) are quoted in support.

The paper refers to difficulties which can arise in reconciling the needs and wishes of parents and children but does not elaborate. However, this is potentially a major issue, if parents want a break but the child is unhappy with the options available. Research has shown that some disabled children feel intense homesickness and unhappiness while on short breaks, even in family link schemes (Oswin, 1984, Stalker 1990, SCIE 2004). This is not always picked up by care staff and, if it is, they may decide that parents' need for a break is more pressing than the child's temporary unhappiness, especially if the break may enable parents to continue caring.

3.6.3 The Care 21 report

The Scottish Executive commissioned the Office for Public Management to produce a report which would inform its thinking about how best to support unpaid carers over the next ten years. The resulting *Care 21* report (OPM 2006) described caring as an 'equalities issue' and set out what it called a rights-based approach towards carers. It recommended that carers should have a statutory minimum entitlement to short breaks, a proposal which later appeared as an SNP manifesto commitment. However, this begs the question of what rights children will enjoy if they do not want short breaks or are unhappy with the service provider, timing or any other aspect of the arrangements. Although *Care 21* stated that the cared-for person has a right to refuse care from anyone s/he does not feel comfortable about, it would be difficult for many children to assert themselves in this way (even if they were aware of this 'right').

Responding to the report, the Scottish Executive (2006a) identified 'respite' as one of its four priorities for carers, with a focus on preventative, personalised care. However, "the primary focus will be on breaks from caring for the benefit of adult carers" (p3). Fortunately, by the time national guidance was issued (Scottish Government 2008b) the message had shifted, with short breaks being described as designed to enhance quality of life for both parties. For children, it should offer

...opportunities to participate in activities with friends and peers, vital to their personal, social and educational development, contributing to self confidence and well-being (p.2).

3.6.4 National Strategy for Carers

This was followed by the National Strategy for Carers 2010-15 (Scottish Government 2010h), covering a range of topics. In relation to short breaks, echoing the fSDC Task Group paper, it states that disabled children “can benefit from participation in youth clubs, after-school clubs, sports clubs, and holiday activities” (s.13.14). To address the widely reported shortfall in short breaks, the Government pledged that an additional 10,000 ‘respite’ weeks would be made available by March 2011. Four million pounds were given to local authorities for this purpose although it is not clear how much of the funds were actually spent on short breaks (Shared Care Scotland 2011). The Strategy also stated that the timescale for meeting the SNP manifesto commitment regarding entitlement to ‘respite for those in greatest need’ would be reviewed in 2012.

3.6.5 New funding initiatives

As already noted, in 2009 fSDC had mounted a high profile campaign to highlight /recover £32 million given to Holyrood by Westminster for services to disabled children. Due to lack of ring-fencing, local authorities were not obliged to spend the money in that area and many parents and practitioners reported little increase in provision. In particular there were continuing complaints about lack of short breaks (Williamson 2010). In response, the Government allocated an extra £5 million pounds to develop short breaks over the period 2010-2015, this time within the voluntary sector where there could be confidence the funds would not be diverted to other areas. A Short Breaks Fund was set up in December 2010, administered by Scotland’s National Carers Organisations. Although open to all user groups, applications for short breaks for disabled children were ‘particularly welcome’. Information for applicants set out clear good practice guidelines, stressing that short breaks must be a positive experience for parents and children, should enable people to live ‘normal, fulfilled lives’ and be refreshed ‘through outside interests, holidays or other activities’. The Fund would take a preventative approach, aiming to offer planned breaks rather than crisis intervention. Innovative and flexible models of support were to be welcomed. These principles were reflected in the criteria for awarding funds. In the event, the majority of applications relating to children did indeed offer attractive, child-centred and socially inclusive breaks⁵. Towards the end of 2011, recognising that children with complex, multiple support needs were missing out on short breaks, the Scottish Government announced a further £2 million for the Short Breaks Fund, this time specifically to benefit families with ‘severely disabled’ children. This was

⁵ The author was a member of the Short Breaks Fund Assessment Panel at that time

divided into two separate ‘pots’, *Better Breaks*, administered by Shared Care Scotland, targeted money at third sector agencies to develop additional and creative short breaks, while *Take a Break*, administered by the Family Fund, can award money directly to families. Guidance again sets out helpful principles, highlighting that funding is intended to produce positive outcomes for carers and children equally, improving their quality of life, opportunities and well-being. The *Take a Break* funds are to be awarded on a first come, first served basis (provided applications meet the criteria). There is a risk that better informed parents, those who are under less stress and those already in touch with services are more likely to be among the first to hear about and respond to such a call.

While the recent funding initiatives to increase short breaks for disabled children are clearly to be welcomed, the amounts involved are very modest in comparison with the £800 million made available for short breaks in England for the period 2011-15, as part of the Early Intervention Grant.

3.6.6 Reduction in children’s use of overnight breaks

Strangely perhaps, Scottish Government (2011d) statistics for ‘respite’ provision in local authorities for the period 2010-2011 show that short breaks for children have decreased by 300 weeks, or 1.23%, since 2009-2010, despite a slight overall increase (0.69%) across service user groups. This relates to declining use of overnight provision by children, the reasons for which are not clear but need further investigation (Shared Care Scotland 2011). It may be that parents and/or children are choosing not to use overnight breaks, possibly because more daytime options have become available or, probably more likely, families are making their own arrangements to purchase overnight short breaks through SDS (Shared Care Scotland 2011). The statistics also highlight the uneven provision across Scotland, reflected in recent headlines in the *Herald* newspaper about a postcode lottery of short breaks for disabled children.

3.6.7 Recent research

Only two recent studies about short breaks for disabled children in Scotland have been identified, both evaluations of services provided by Action for Children (AfC). First, McConkey (2011) evaluated three services, one in Wales and two in Scotland, offering both short residential breaks and intensive support at home to families with disabled children whose behaviour is ‘severely challenging’. The research looked at the experiences of 123 young people and their families, most from disadvantaged backgrounds, a high proportion being single parents and all facing a range of challenges, including risk of family breakdown. The young people were mostly teenagers and two thirds were on the autistic spectrum.

Keyworkers were asked to rate the young people (with numerical scores) in terms of various skills and behaviour, over a six month period. A significant

number were said to show improvements in communication skills and personal care while about half had reduced stereotypical behaviour and aggression. In terms of social inclusion, the young people reported that what they most enjoyed while in the unit was going out and doing different activities in the community. A range of pursuits were reported but few involved making social contact with other people. McConkey commends the services for increasing the young people's opportunities to take part in community activities but concludes that their social inclusion remains limited and that there is a need to find ways to build personal relationships both among the young people and with others. There was a lack of support to enable friendships struck up within the unit to continue outside the service. It is notable that what the young people most disliked about the unit was missing their family and home.

The other evaluation of AfC services was conducted by Loughborough University (AfC 2011a). This looked at eight short breaks services including one in Scotland and aimed to examine their impact on disabled children and families and also AfC's record in communicating these outcomes to other agencies. Findings relating to children included success in enabling them to try out new activities (families reported that this helped reduce their social isolation), effectiveness in seeking and acting on children's views and wishes, children developing new life skills, greater self-confidence, improved emotional well-being and simply having fun.

3.7 Transition to adulthood

3.7.1 Introduction

In policy and practice terms, moving from children's to adult services is wide-ranging and complex. For parents of disabled young people in Scotland, recent experiences have been 'unanimously negative' (Haughey 2011) and 'often caused anxiety and distress' (key informant, Nov 2011) and all too often, a narrow range of future options is considered, with the young people not fully involved in decision making. Supporting social inclusion is not usually given high priority in the planning process (key informant, Nov 2011) despite young people's priorities at this time often focusing on leisure, lifestyle, making new friends, socialising and having fun (SHS Trust, 2002).

3.7.2 The policy framework

There are many documents and initiatives relating to this topic, some being universal policies in which disabled young people, or those with additional support needs, are a priority group, others relating exclusively to them. The Additional Support for Learning (ASL) (Scotland) Act 2004 and the revised Code of Practice (Scottish Government 2010f) lay out the framework for transitional planning. Education authorities must take the lead but should approach, for information, any other agency likely to be involved with the

young person once s/he has left school. According to the Act's explanatory notes:

Authorities must, when considering the adequacy of support to be provided to the individual, take account of that information and also any provision other than education that the local authority are likely to provide themselves on the child or young person ceasing school education. Authorities must also seek and take account of the views of the child or young person and their parents. This all should be done at least 12 months before the child or young person is expected to leave school, so it could be done when the child is 15 years old or even earlier (Scottish Executive, 2004a: 27).

In 2006, worried about the 20,000 young people not in education, employment or training who need additional support to access such opportunities (the so-called NEETs), the Scottish Executive launched its More Choices, More Chances strategy (Scottish Executive 2006b). Young disabled people and those with mental health issues were identified as among those most likely to become NEET. Five key areas of activity were identified to tackle the problem, with a focus on learning opportunities being tailored around individual need. This was followed by Partnership Matters (Scottish Government 2009), an updated guide for local authorities, NHS boards and voluntary sector partners responsible for supporting young people with additional needs at college or university.

In 2010, Scottish Government launched the Post-16 Learning Choices Initiative (Scottish Government 2010i) which committed to making all 16-18 year olds a 'suitable high quality offer of learning' in an education, training or employment setting. There was to be a particular focus on 'vulnerable groups' including young disabled people. Three critical elements were to be present – the right learning opportunity, the right support to take up and sustain it (such as information, guidance and advice from Skills Development Scotland) and the right financial support. These elements should be available not only when young people leave school but in any subsequent transitions they might have. Effective planning for disabled children must start in S3 and a placement offer be made at least six months prior to their school leaving date. Also in 2010 the Government announced new funding for Modern Apprenticeships and training places for 16 and 17 year olds, taking the total allocation to over 40,000 in 2011-12 (Scottish Government 2010j). The Scottish Transitions Forum (2011) suggests that these initiatives should give young people with learning disabilities a better chance to access work.

The Post-16 Reform Programme continued with the publication of *Putting Learners at the Centre - Delivering our ambitions for post-16 education*. Here the Scottish Government (2011e) commits to widening

participation in both FE and HE, including for people with additional support needs. It will continue to support local authorities and their partners to improve transitional planning especially implementation of the Additional Support for Learning (Scotland) Act. Every 16-19 year old is to have a place in learning or training by the end of the current financial year. Significantly for young disabled people, learners are guaranteed a minimum income of £7000 pa with those from disadvantaged backgrounds at the top of the queue.

3.7.3 Research and commentary on policy implementation

Confusion and lack of clarity

An HMIE (2007) review of the implementation of the 2004 Additional Support for Learning (Scotland) Act found significant difficulties in post-school transitional planning and FE provision for young people with complex support needs and those with behavioural issues. The Government consequently created a two year National Development Officer post to identify causes and solutions. His analysis (Haughey 2011) makes sober reading and is drawn on below, along with key informant comments. There seems to be a consensus that transition policies, considered individually, are generally appropriate and helpful, with GIRFEC offering a best practice model. However, a major problem for planners, practitioners, parents and young people is the plethora of policy documents and initiatives and how they relate to one another. This has created confusion, with families struggling to find a clear pathway through the process. A succinct summary of service providers' responsibilities and young people's rights is missing. When the Scottish Transitions Forum suggested that the Scottish Government produce such a statement, the response was that the policy framework was too complex to allow it. A lot of attention and activity on transition is in progress within Scottish Government but there is concern among service providers that this may complicate rather than clarify and consolidate the situation.

Transitional planning

Despite legal requirements, schools often start transitional planning too late. Other agencies are not always involved at an early stage, with the result that, for example, a college place cannot be taken up because no transport has been arranged or no provision made for personal care. Evidence from England suggests that young disabled people who are looked after and accommodated fare particularly badly in this regard (Priestley et al 2003). These authors found that it was common for housing and college placements to be made at the last minute, with young people getting little information or choice.

Despite their duty to seek information from other agencies, schools are often unaware of the range of options available to young people. In addition, despite Government policy that Skills Development Scotland should raise

young people's expectations and aspirations, especially for those needing additional support, negative assumptions may be made about some young people's potential, with employment options seldom considered (see also Beyer et al 2008). At the same time, the economic recession has clearly affected the jobs market. In this context, the Government's statement that a range of agencies is responsible for ensuring a sufficient range of learning/employment provision is available to young people appears somewhat disingenuous (Scottish Government 2010i).

Underlying many of these issues is the old chestnut of poor partnership working, including cultural differences between children's and adult services.

Haughey found that special schools were generally better at planning than mainstream schools but could still improve. Transitions were especially poor for pupils at residential special schools. However, some local authorities are commended for good practice - Highland, Edinburgh and Fife.

There are numerous reports of parents and young people not feeling involved in planning. Some parents with children at mainstream schools told Haughey that no transitional planning meeting had taken place. Where it had, there was typically no preparation for young person or parents, the professionals present had not met the young person before, a pre-set agenda and standard procedures were followed, parents felt they had no voice, were not listened to and that insufficient time was allowed to discuss issues fully. Young people also express dissatisfaction with transitional planning meetings, feeling they are 'invisible' and that decisions are made by adults (Cameron and Murphy 2001, SHS Trust 2002, Haughey 2011).

There can be a lack of support for those with communication impairments to express their views. Using Talking Mats, Cameron and Murphy (2001) sought the views of young people with communication impairments about what mattered to them in terms of transition. The authors found the young people's choices were not 'unreasonable, excessively costly or impractical', with moving on to college and keeping in touch with school friends high priorities. Some expressed views which were 'new' to their carers.

It has also been suggested that parents sometimes support options perceived as offering safety, security and protection for their sons and daughters but which may compromise the young people's ability to choose for themselves and become more independent. Some young people in the Real Choices study described how their parents tended to treat them as younger than they were, not allowing them to stay up late or try new activities (SHS Trust 2002).

Further Education

A consultation about FE colleges with 30 young people with communication, sensory, physical and / or learning impairments found that 'the situation in Scotland ...is, in general, very poor' (Miller and Aitkin 2005:1). Problems included a lack of information and transparency about FE options for school-

leavers, provision-led rather than needs-led placements, FE staff lacking communication skills, specialist support with communication often being unavailable and many difficulties around funding.

Nevertheless, when working well, FE colleges can offer young people with learning disabilities opportunities to develop skills and prevent or reduce social isolation (SCLD 2011). It is therefore a matter of concern that across Scotland, part-time courses for this group were cut by over a third in 2011. There was a slight increase in full-time courses but most young people attend part-time. This is related to a reduction in the Scottish Funding Council's financial allocation to colleges which decided on an individual basis how to implement the cut, coupled with a drive by Scottish Government to increase accredited courses leading to employment (SCLD 2011). This is likely to disadvantage people with learning disabilities and those with more complex needs. The Scottish Consortium for Learning Disability has called for evidence that the cuts to courses have been subject to Equality Impact Assessments.

4. Specific groups of children

This section identifies two groups of children who are relatively neglected in research and/or policy and are particularly prone to social exclusion. This is true of various other groups as well but it is not possible to examine them all here. They will be highlighted in Section 5.

4.1 Deaf children

This section highlights a few initiatives that have had an impact on deaf children. The National Deaf Children's Society was awarded a Lottery grant from 2008-2011 for a project entitled *Who Am I?* This had two aims: first, to improve the self-esteem of young deaf people aged 13 to 19, encouraging them to feel comfortable with their deafness and confident about being independent in a hearing world; second, to help their families feel positive about the young person's transition toward independence and support them through it. The project report (NDCS Scotland 2011a) highlights a need for positive role models, support to make new friends, sometimes initially involving parents in social events because some young people do not have the confidence to attend alone, and follow-up support to maintain friendships.

In another initiative, 12 young deaf people aged 14-18 attended a participation and climbing day organised by NDCS Scotland (2011b). All were in mainstream educational settings. They identified three areas where they experienced barriers to doing what they wanted – communication, social activities and sports and, thirdly, school/ college/ university. These echo the findings of Dalton et al (2001) over ten years earlier regarding obstacles reported by young deaf people in Edinburgh and the Lothians. Lack of support with communication prevented some young people from playing football and going swimming while lack of deaf awareness among the public at large led some young people to avoid using mainstream facilities like cafes and pubs. The participants had various suggestions for tackling these barriers, such as becoming more assertive, wider availability and use of interpreters, teaching deaf awareness, a 'deaf awareness light' approach for sports providers, more loop systems, regular subtitles for films, using technology to help communicate and hanging out with other young deaf people "who understand".

The need to be aware of young deaf people's vulnerability to mental health issues is highlighted in a consultation undertaken with various groups of children to inform an NHS draft framework for children and young people's mental health indicators (Elsley and McMellon 2010). The participants felt they were not consistently heard and listened to. They had very clear ideas about what was / was not 'fair' in their lives, several having experienced bullying and discrimination. Yet again, friendships and relationships were described as significant and the family was central. Trusted adults in professional roles were also appreciated, notably teachers.

4.2 Children with learning disabilities and mental health issues

This section reports information given by key informants from the National Child and Adolescent Mental Health Network for Scotland. Children with learning disabilities have a much higher risk of mental distress than those without learning disabilities (incidence is estimated at 1 in 3). Particularly affected are children from disadvantaged backgrounds, especially those who have additional physical impairments or poor health and those whose mothers may also have learning disabilities and/or mental health problems. These children have often experienced a series of adverse life events, sometimes including community bullying of the whole family. This can stop children playing in the street (they may not have a garden) and prevent the family going out together. Transport is often difficult because parents cannot afford to pay for it and/ or the children cannot travel independently on public transport. Those with autism are likely to experience difficulty accessing busy facilities like swimming pools and cinemas and in some cases, 'challenging behaviour' is a further barrier to inclusion.

Despite high levels of need, there is a paucity of mental health provision for children with learning disabilities across Scotland: they are often seen as lying outwith the remit of both community learning disability teams and child and adolescent mental health services (CAMHS) (Fitzsimmons et al 2011). Some CAMHS teams will not see these children and those that will do not always have the specialist expertise required. Even the best developed learning disability/ CAMHS teams lack the resources available south of the border, falling well short of recommended staffing levels. This reflects a lack of strategic focus on children with learning disabilities and mental health issues at national level. They were explicitly excluded from the Child Health Support Group In-Patient Strategy (Scottish Executive 2004b). It is estimated that 12,000 children with learning disabilities in Scotland currently need access to appropriate mental health services (Fitzsimmons et al 2011). Without this, their quality of life, already seriously impaired, will deteriorate further, placing them at high risk of school and community exclusion (children with emotional, behavioural and social difficulties are over-represented among those excluded from school).

On the more positive side, the GIRFEC framework is seen as a good way forward for working with these children. Befriending, buddying and short breaks can all be very helpful, particularly when they encourage use of public transport, mainstream leisure facilities and increasing social inclusion. Many more of these resources are needed.

5. Key points and next steps for the Commissioner

This final part of the report draws out key points from the review and suggests next steps for the Commissioner to consider. We recognise that the Commissioner will not be able to take on all of them. The first three below contain proposals for substantial pieces of work. The remainder offer options for further consideration.

In the previous sections we examined the main findings from key research studies and findings from analysis of policy areas, and discussed specific groups of children who are particularly prone to social exclusion. Here we will be looking at possible next steps that could be taken in relation to:

- Social and economic advantage
- Bullying and prejudice
- Disabled children's views and voices
- Friendship and social activities
- GIRFEC
- Poor national data about numbers, needs and characteristics
- Education
- Self-directed support
- Short breaks
- Transition to adulthood
- Gaps in current research,
- Promoting rights and social inclusion

5.1 Social and economic disadvantage

High living costs, low incomes and, in many cases, poverty are probably the greatest barriers to social inclusion for disabled children and their families. This is exacerbated by the current financial crisis, cuts to services and reform of welfare benefits. As well as debarring many disabled children from use of mainstream social activities and opportunities simply because they cannot afford them, the downturn has also affected the jobs market for school leavers, availability of FE courses and may reduce what can be achieved through self-directed support.

Disabled children and young people have been seriously disadvantaged by the Concordat between the Scottish Government and COSLA. First, they have lost out on monies transferred to Holyrood from Westminster intended for disabled children's services; secondly, the Scottish Government cannot ring-fence any further monies for similar purposes and thirdly, it cannot ensure the consistent and equitable implementation of policies across Scotland within the current arrangements between national and local government. Thus the 'postcode lottery' of provision is set to continue.

The Commissioner should prioritise tackling the social and economic disadvantage facing disabled children. For example, by making the case

for continuing financial support for families with disabled children within the Welfare Reform Bill, reminding the UK Government about their reassurances that benefits to disabled children will not be reduced. This may be something the Commissioner could take on in conjunction with the other UK Children's Commissioners.

Other options for action could include:

- making the case against cuts in services and for the support for disabled children to be firmly embedded, with ear-marked funding, within the forthcoming Children's Services (Scotland) Bill
- talking to employers about improving availability and take-up of jobs for young disabled people and encouraging mainstream facilities such as sports centres and entertainment venues to give free entry to disabled children and/or their carers.

Key action:

- **Prioritise tackling the social and economic disadvantage facing disabled children**

5.2 Bullying and prejudice

Bullying of disabled children is widespread as is prejudice towards disabled people generally. Thomas (2007) coined the term 'psycho-emotional disablism' to refer to the hurtful and hostile behaviours frequently directed at disabled people which, she argues, have a cumulative, damaging impact on what an individual feels s/he can be or become. It is also worth noting that Quarmby (2011) in a study of 'hate crime' against disabled people, found that in some cases where an adult had been harassed or even horrifically abused, s/he had been at school with the perpetrators and this was where the bullying had begun. These findings show an urgent need to deal with bullying of disabled children more effectively.

In collaboration with other relevant agencies, it is recommended the Commissioner establish and lead a high profile education and awareness raising campaign about disability equality in relation to disabled children and young people. This should be aimed at the general public but also targeted at school children in order to reduce current levels of bullying and promote more positive attitudes towards disabled people in the future. Involving some disabled (possibly high profile) adults to act as positive role models for disabled children would be a bonus.

Key Action:

- **In collaboration with other relevant agencies, establish and lead a high profile education and awareness raising campaign about disability equality in relation to disabled children and young people**

5.3 Disabled children's views and voices

Across the policy areas reviewed in this report is a common theme of children and young people having a low profile and/or being inadequately involved in decisions affecting their lives. They have been relatively invisible in GIRFEC to date. There is need for better consultation and collaboration with disabled pupils about their individual learning plans. It appears common for young people (and their parents) not to be properly involved in transitional planning, and there is a risk that children's views or feelings may be over-ruled within SDS and short breaks. These findings contravene both children's rights, within statute and the UN Conventions, to express their views and service providers' duty to take these into account. Related to this is the paucity of independent advocacy for disabled children across Scotland, albeit the Scottish Government (2011f) is currently consulting on improving advocacy for children and young people.

In collaboration with other agencies, the Commissioner should set up and support a national young disabled people's forum in Scotland. This could advise the Commissioner on how to take forward the recommendations in this report and be available to service planners and providers at local and national levels as an advisory group. It could, importantly, identify its own issues and priorities. Such a group was and in theory still is planned by the fSDC Liaison Project but the future of the project beyond March is currently uncertain.

Other options for action could include:

- The Commissioner could also encourage mainstream children and young people's forums to include more disabled children.
- Through the current Scottish Government consultation, the Commissioner could encourage the development of more independent advocacy for disabled children and young people, especially in those parts of Scotland where there is currently little or no provision.
- Highlight the need both for new projects dedicated to disabled children and for existing projects to include more disabled children.

Key action:

- **In collaboration with other agencies, the Commissioner should set up and support a national young disabled people's forum in Scotland.**

5.4 Friendship and social activities

When disabled children are asked about what is important to them, friends and fun are recurring themes. However, difficulties making and keeping friends and accessing social and sports activities are frequently reported. Some young people want to meet others with the same conditions to discuss shared experiences. Lack of support with communication is a major barrier for some, hindering their participation in social and sporting activities and making friends, and not helped by a shortage of speech and language therapy. A paucity of accessible transport and, for some young people, not being able or allowed to travel independently increases their social isolation. Delays in getting aids and equipment, including wheelchairs, restrict some children's activities. Others do not have enough money to take part in social events.

Parents are often disabled children's best advocates and fight hard for them to have valued and fulfilling lives. However, young people sometimes feel their parents are over protective and restrict them from joining in age-appropriate activities. Young people want more support to socialise but would generally prefer this to be provided by people near their own age. While some require intensive support or close supervision, others may be subject to an unnecessary level of adult surveillance.

Disabled young people need better sex education and accessible information about related issues such as informed consent and contraception. This is important both for any relationships they choose to have but also because they are at increased risk of abuse compared to non-disabled young people (see Stalker et al 2010).

In summary, the barriers facing disabled children around friendship and social activities are many and complex. The key action under 5.2, for a consciousness-raising campaign, would go some way towards addressing some of these factors.

Option for action

- The Commissioner could work with mainstream recreation and social providers to build their capacity to welcome and include disabled children, highlighting the need for support with friendship, communication and accessible transport and raise the issue of sex education with local education authorities.

5.5 GIRFEC

GIRFEC appears to be universally seen as offering a positive way forward for working with disabled children, with the potential to increase their social inclusion (and tackle many of the problems in service delivery long identified by parents). The 'Included' well-being indicator requires practitioners to recognise and overcome barriers to children's social inclusion. Disabled children have had a low profile within GIRFEC to date

although this may soon be remedied with the production of a new disability-specific Practice Briefing and/or additional tools to support practitioners working with disabled children. It is important that all elements of GIRFEC are applied to these young people, with flexibility and adjustments as appropriate to individual need. Despite the GIRFEC focus on seeing children holistically, materials to date tend to present disabled children as vulnerable. The Early Intervention model advocated by GIRFEC is important in identifying and tackling any problems before they reach crisis. However, it is unclear how far services are able to work in this way in the current economic climate, given that both parents and agencies report that often help is only available when families reach crisis. This may increase the likelihood of residential or segregated services being used, compromising the children's inclusion and, if unfamiliar to the child, risking homesickness and distress.

No specific actions on GIRFEC are recommended for the Commissioner because work is already being taken forward by others and this was not identified as a problem area. However, it is worth noting the importance of GIRFEC taking a holistic view of disabled children, highlighting their strengths and rights as well as their needs, along with the importance of proactive preventative work with families. Staff at all levels would benefit from undertaking training in disability equality and communicating with disabled children.

5.6 Poor national data about numbers, needs and characteristics

The National Review highlights the lack of reliable, comprehensive information about numbers, characteristics and needs of disabled children in Scotland. Indirectly this is a barrier to promoting social inclusion since these data are required to inform planning in schools and services. Issues include lack of a single shared definition of disability, inconsistent recording of impairment and poor data collection. Absence of clarity about definitions may lead to disabled children being marginalised.

No action is recommended on this from the Commissioner as it is already being taken forward by Scottish Government.

5.7 Education

Despite recent legislation aiming to make mainstream education the default option, special schools rolls have not dropped significantly. Children with additional support needs, notably those with social, emotional and behavioural difficulties, figure disproportionately among school exclusions, indicating a need for much better support particularly within mainstream schools. In addition, current teacher training and CPD do not include enough material on including disabled children and what courses exist are not compulsory for all students or qualified teachers.

Use of Co-coordinated Support Plans is very inconsistent across authorities and overall much lower than the Records of Needs which they replaced, indicating that many children may not be getting the support they are legally entitled to. While parents and pupils have redress to the Additional Support Needs Tribunal, less articulate or confident parents are less likely to take this route.

Various features of the new Curriculum for Excellence as it may be applied to disabled children give cause for concern. In particular, it is not clear if disabled children will have access to all parts of the curriculum. The 'elaborated curriculum', for those with complex or significant learning needs, may still be drawn on despite being based on a behaviourist model which does not fit well with the active engagement ethos of CfE.

CfE does not include material on disability equality. It would hugely benefit disabled children and their non-disabled peers if this were routinely taught in schools.

There are problems meeting some disabled children's personal care and medical needs at school. Teachers and support staff do not always or are unable to provide assistance, with the result that some parents are coming into school on a regular basis and children's participation in daily school life may be jeopardised.

Adults (both parents and professionals) do not always recognise disabled children's ability or potential and in some cases may have low expectations of what they can achieve. This is reflected in disabled young people's relatively negative assessment of what they will achieve in terms of academic qualifications and future careers. Some feel they are being held back academically at special schools.

Options for action

- The Commissioner may wish to consult with the General Teaching Council for Scotland to urge that any changes in the structure of ITE courses should work towards more, not less, content in the area of Additional Special Needs and do not disadvantage those with more complex needs.
- He could also discuss with local authorities the need to support teacher professional development through accredited and research based courses.
- Other issues he could take up are the inclusion of disability equality teaching in schools (this can be linked to the wider campaign proposed above at 5.2) and ensuring children's personal care and medical needs are met appropriately in school.

5.8 Self-directed support

There is a view that SDS holds the key to social inclusion, with its potential to divert children away from segregated settings and formal services and into flexible, mainstream opportunities of their own choosing, supported by people of or near their own age. SDS may not be an unmitigated good however, with commentators warning about unregulated PAs, variable quality of care, a risk that professionals take the lead and that some authorities are using SDS as a ‘smokescreen’ for service cuts.

Option for action

- The Commissioner is likely to be broadly supportive of SDS but may wish to make recommendations to the Scottish Government that statutory guidance accompanying the new legislation sets out how quality of care is to be monitored, and how young people will be informed about their rights under the new Act, with options for supported decision making available, preferably involving independent advocates where appropriate. There should be opportunities for young disabled people to be strategically involved in local development.

5.9 Short breaks

Short breaks can also offer children flexible, mainstream community based activities on a one to one basis or with other young people. Some forms of short break help expand children’s horizons and develop personal and social skills. It is encouraging that recent policy and funding developments encourage these developments, albeit on a modest scale.

Barriers associated with short breaks include shortage of provision and crisis use of ‘respite’ care, the latter likely to be in residential settings with which a child may not be familiar. There is evidence that children often feel homesick in residential and family based short term care, sometimes severely so, and that this is not always addressed. Partly linked to this, there is a potential conflict between parents’ desire (and sometimes need) for a break and children’s ability to choose if, when and where they have a break.

Option for action

- The Commissioner is likely to be broadly supportive of flexible, child-centred short breaks. The SNP’s manifesto made a commitment to continue to provide funding for increased respite provision each year and to increase its funding for short breaks for families who have severely disabled children. The Commissioner may wish to have discussions with the Scottish Government about how these commitments will fit with children’s rights to express their views about short breaks and have these taken into account.

5.10 Transition to adulthood

Of the various policy areas reviewed, transition to adulthood/ adult services is perhaps the most problematic. It is difficult for families and sometimes professionals to map a clear path through the raft of policy initiatives in this area and to understand how these join up. The lack of a concise policy guide setting out service providers' responsibilities and young people's rights is a barrier to smooth transition.

The Scottish Government has developed a range of policies to reduce the number of young people not in education, employment or training. To date however, there is little evidence that supporting social inclusion is uppermost in professionals' minds when planning young disabled people's transition to adult services. There seems to be a lack of knowledge within schools about the range of potential options available for young people to move onto: to promote social inclusion, more attention should be paid to supported employment and paid work, albeit within the limitations of the current economic climate. Transition planning often starts too late and is marred by poor inter-agency collaboration. This has led to placements falling through.

Options for action

- The Commissioner's office, in collaboration with the Scottish Transitions Forum, could consider producing the simplified policy overview/ guide setting out children's rights and service providers' responsibilities which has been identified as much needed but missing.
- In England, the Department for Children, Schools and Families (now the Department for Education) set a target that all authorities should have a transition process in place by 2011 which must meet minimum standards. The Commissioner could lobby the Scottish Government and COSLA to follow suit, as Cheseldine (2010) has proposed.

5.11 Gaps in current research

There is a need for research about:

1. The impact of the Equality Act 2010 on disabled children and young people
2. Effectiveness of strategies for tackling disablist bullying
3. The impact of SDS on disabled children
4. The pattern of short breaks for disabled children across Scotland with a comparison of the benefits and limitations of different kinds
5. The reasons for the apparent decrease in use of overnight short breaks by disabled children

6. The extent to which disabled children are being included within GIRFEC and what difference this is making in terms of social inclusion
7. The reasons for the high numbers of disabled children (particularly those with social, emotional and behavioural difficulties) being subject to school exclusions and ways to reduce this
8. The implementation of the Curriculum for Excellence for children with complex needs.

Option for action

- The Commissioner could consider research in any of these areas. However, as most relate to policy implementation and require sizeable studies, it may be more appropriate to encourage other bodies, such as Scottish Government, the Equality and Human Rights Commission and charitable trusts, to do so.

5.12 Promoting children's rights and social inclusion

The review has identified a number of relatively neglected groups of children. These are (in no particular order):

- Children with mental health issues generally
- Those with learning disabilities and mental health issues
- Deaf children
- Looked after disabled children
- Disabled children from black and ethnic minority families
- Children with communication impairments
- Children spending long periods in hospital
- Children at residential school.

Two other potentially neglected groups, to whom we have found no Scottish reference, are disabled children from travelling families and those who are Lesbian, Gay, Bisexual and Transgender.

Option for action

- The Commissioner could decide to focus on promoting the rights and social inclusion of some of these neglected groups. A strong case exists for supporting any or all of these children although selecting some over others may be difficult.

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