

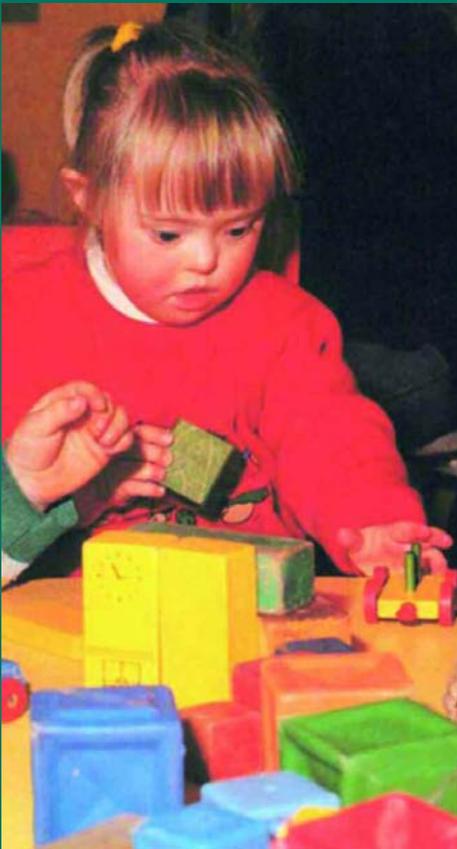


# Changing childhoods?

*The same as you?*

National Implementation Group

**Report of the Children's Sub Group**



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scotland  
SCOTTISH EXECUTIVE

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# Introduction

This report, one of a series of supplementary reports to *The same as you?* review of services for people with learning disabilities<sup>1</sup> focuses on improving services and supports for children and young people with learning disabilities and with autism spectrum disorder in Scotland.

## **Our working definition of the term learning disability**

In *The same as you?* report, the definition of learning disability is 'a significant lifelong condition which has three facets: reduced ability to understand new or complex information or to learn new skills; reduced ability to cope independently; and a condition which started before adulthood (before the age of 18) with a lasting effect on the individual's development' (*The same as you?* 2000 p.103).

It includes people with autism spectrum disorder. It does not include children with specific learning difficulties, such as dyslexia. However, the person-centred practice identified in this report will be of benefit to all children, not just children with learning disabilities.

## **Children with learning disabilities and autism spectrum disorder in Scotland**

The estimated number of children aged 18 years and under in Scotland, as at 30 June 2004, was 1,132,000<sup>2</sup>. One in 40 of these children may have a learning disability. Many will have a mild learning disability and require a little additional support. However, four in one thousand of the population will have moderate to profound disabilities and require significant additional support.

Using prevalence studies that estimate 60 per 10,000 children with autism spectrum disorder, there are an estimated 7,614 children and young people under 19 in Scotland with autism spectrum disorder. A service audit<sup>3</sup> in 2003 identified 3,412 individuals, but the information identified by local agencies varied significantly and it is recognised that these figures were an underestimate.

While the number of children and young people in Scotland is predicted to decrease over the next 10-15 years, it is clear that the number of children with severe and complex disabilities is increasing. Many young children with profound and multiple disabilities are now surviving through childhood and into adulthood. It is predicted that there will be an increase of 1% per annum in this group between 1998-2008.

Children with learning disabilities are also at greater risk of experiencing poverty than children without a learning disability. In 1999 it was estimated that 44% of 5-15 year olds with learning disabilities were living in poverty compared with 30% of children without disabilities<sup>4</sup>. Poverty has a pervasive impact on the health and mental health of children and parents. The experience of poverty is likely to be associated with poor parental health and wellbeing and poor child health and wellbeing. More children with learning disabilities live with lone parents and are disproportionately represented in ethnic groups.

Many parents of children with disabilities confirm that the birth of a child with a disability is generally still treated differently from the birth of a child with no disability. There is a real shift towards involving people with disabilities and family members in decisions that help shape their lives. However, it is still the case that for many children and adults with learning disabilities and autism spectrum disorder, life's expectations are markedly different to those of other people. Different expectations of school inclusion and attainment in childhood also lead to prospects for full civic inclusion and fruitful employment that are still lower than they should be.

By incorporating many individual stories, this report reflects on the current experience of being one of these young people with a learning disability or autism spectrum disorder in Scotland in 2006. Taking into account the cultural, educational and social policy context, the report aims to highlight the ordinary experience of being a young person with learning disability, and the changing expectations of these young people and their families for the future.

The report also highlights the policy initiatives and good practice opportunities that exist in Scotland to ensure that more young people with learning disabilities and autism spectrum disorder get the chance to think well of themselves and fully contribute at an individual, community and civic level in the life of Scottish communities.

Peter's story describes how being excluded affected his life.

*My name is Peter and I am a member of People First (Scotland). I would like to tell you about my experience of school. When I was young I was labelled as a person with learning difficulties.*

*I went to a special school in a special bus. The bus came right up to the street to pick me up. It was known as my bus. The school and the bus marked me out as being different from the other children. My school was right next to an ordinary school. At play times the children from the other school used to stare at us through the bars as if we were animals. They did not know us as people, so they did not know how to treat us.*

*I think that other children treated me like this because they thought I was different. They would have got to know me as a real person if I had gone to the same school. They would have learned that people are people even if they don't do things as quick or if they look a bit different.*

*Nobody ever sat me down and asked what I would like to do when I left school. It is important to learn skills that help you get a job. I feel we did not get this chance.*

*I feel that if The same as you? document had been around then, I could have had a better education which was more suited to what I needed and I may have had the opportunity to continue to attend a mainstream school close to my home. The recommendations from The same as you? might mean that the right supports were in place to allow this to happen.*

*This would have meant that the other children would have stayed in the area that I lived in. They would have got to know me better and I would have had the opportunity to make more friends instead of being seen as different and always being bullied.*

*If you are told time and time again that you can't do some things then you start to believe this. If I had been given a better education I would have had more self-belief and self-confidence and may have felt that I had something of value to offer to my community.*

### **About *The same as you?***

*The same as you?* was published in May 2000. It was the first major review of learning disability services in Scotland for over 20 years. The success of *The same as you?* was its inclusive approach, which made it much more than a review of systems and services. It was a consideration of individual lifestyles.

People with learning disabilities and family carers created the vision for the future that took account of individual needs and involved them in decisions about their lives. All of the recommendations in *The same as you?* are guided by seven principles:

- People with learning disabilities should be valued. They should be asked and encouraged to contribute to the community they live in. They should not be picked on or treated differently from others.
- People with learning disabilities are individual people.
- People with learning disabilities should be asked about the services they need and be involved in making choices about what they want.
- People with learning disabilities should be helped and supported to do everything they are able to.
- People with learning disabilities should be able to use the same local services as everyone else, wherever possible.
- People with learning disabilities should benefit from specialist social, health and educational services.
- People with learning disabilities should have services which take account of their age, abilities and other needs.

Unless otherwise specified, all of *The same as you?* is about people with learning disabilities and people with autism spectrum disorder **of all ages**. The 29 recommendations aim to ensure people with learning disabilities have a better quality of life.

## Why the Children's Group was set up

Implementation of *The same as you?* nationally and locally involves numerous stakeholder groups. At national level, the Scottish Executive supports *The same as you?* National Implementation Group (SAYIG), the Users and Carers Group, and the Partnership in Practice (PiP) Network. An Autism Spectrum Disorder Reference Group is also providing advice and support in taking forward the recommendations of the Public Health Institute of Scotland's *Autistic spectrum disorder Needs Assessment Report*<sup>5</sup>.

Since 2002, SAYIG has set up a number of short-life working groups to address issues that are priorities for successful implementation. One such group was the Children's Group.

The Children's Group was set up primarily because of concerns that *The same as you?* was generally perceived as a report about adults, with adult services having responsibility for implementation of its recommendations.

The Group was also set up at a time of significant policy developments relating to children in Scotland, providing an opportunity to ensure these developments take account of the needs of this group of children.

The remit of the Group was:

- To map how *The same as you?* is working for children and young people with learning disabilities and autism spectrum disorder
- To identify current support
- To promote best practice
- To help make all of the recommendations of *The same as you?* happen.

What we achieve in adulthood is shaped by our experiences in childhood. The aims of *The same as you?* for adults can only be fully realised if the principles are embedded in support and services for children and families from the earliest years. Whilst education is a major part of our childhood, so too is our health and wellbeing, family life, play and leisure, and the attitudes of the communities in which we live.

## Who were the members and what did the Group do?

The Children's Group was led by the Scottish Consortium for Learning Disability (SCLD). Members included people with learning disabilities, family carers and others with a professional role in developing policy and promoting children's interests. **Annex A** details members.

From the outset, members considered how the views of children and families should inform the report. With the broad remit and aims of the report, it was felt that best use should be made of the extensive evidence already available. Rather than setting out on further consultation, members worked on a number of tasks that would identify both the barriers individuals face and the ways to overcome them. This work included policy mapping and an analysis of children's views documented in a range of earlier consultation exercises.

The group also carried out a 'rites of passage' exercise, where they mapped the key rites of passage for all children (for example, when you have your first sleep over, when you choose your own clothes, etc.). The information from the exercise is produced at **Annex B**. Members then highlighted and reflected on any differences in the life experiences and expectations of children with disabilities and their families, from birth to the age of 25. Part of the work of the group was to identify the factors and forces which worked for and against families of children and young adults with disabilities as they tried to be like everyone else.

The stories provided by people with learning disabilities and family carers are personal testimonies. Some do not refer to current experiences. However, they give real insight into the impact of attitudes, systems and supports on the everyday lives of children, their parents and their brothers and sisters. We are grateful to everyone who was willing to share their story with us. All stories have been anonymised.

## What does this report set out to do?

- To raise the profile of *The same as you?* and to illustrate how its principles can be applied to all children
- To make sure the interests of children and young people with learning disabilities and autism spectrum disorder are addressed
- To ensure the needs and aspirations of children with learning disabilities and autism spectrum disorder and family carers are taken account of across the wider policy initiatives for all children, with specialist consideration as appropriate

- To highlight examples of good practice for both the statutory and non-statutory sector
- To illustrate what supports are available to children and young people, and family members.

### **Who is this report for?**

*The same as you?* states that Partnership in Practice agreements (PiPs) should provide plans for services for children and adults. These agreements should form part of the community care, children's and health planning processes. The PiP should draw together the information that is already in existing plans to make sure all the agencies involved in planning services for adults and children with learning disabilities can come to an agreement.

The responsibility for implementation of *The same as you?* is for all agencies with a role in promoting and providing services. It does not rest solely with community care. NHS Chief Executives and Directors of Public Health will have an interest in the health inequalities facing people with learning disabilities and autism spectrum disorder. Early Years and Education services need to take account of the needs of these children and their families in providing services and supports for all children. Leisure, housing, transport, and arts and culture agencies also need to ensure mainstream provision is accessible to everyone in their communities.

Local agencies also need to ensure wider community planning frameworks address diversity in the population.



SECTION ONE

**WHAT MATTERS TO CHILDREN**

## Children the same as you

Children with any disability are children first and foremost. One of the parent's who told us their story said:

*'Please treat my son the way in which you would treat your own child – he is no more special to me than my other two children. He is kind, loving, beautiful, sociable, moody, cantankerous, argumentative and above all – just Steven. Please find it in you to see past the "label" and find the child inside who needs you to bring out the best in him.'*

The use of disability terminology in this report is solely to ensure the specific needs of this group of children are understood and addressed.

There is a range of views about how useful definitions are, and how they apply in different settings. However, it is important to have a definition so that people with learning disabilities get the services and support they need, and so that agencies can plan these services better.

*(The same as you? 2000 pp 2-3)*

The social model of disability is described as 'the disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities'<sup>6</sup>.

Disabled people do not face disadvantage because of their impairments, but experience discrimination in the way we organise society. This includes failing to make education, work, leisure and public services accessible, failing to remove barriers of assumption, stereotype and prejudice, and failing to outlaw unfair treatment in our daily lives.

Prejudicial attitudes toward disabled people, and indeed against all minority groups, are not inherited. They are learned through contact with the prejudice and ignorance of others. To challenge discrimination against disabled people we must begin by looking at discrimination against disabled children. Evidence from a number of consultation documents that sought the views of children with disabilities reaffirms their desire for a life the same as other children.

A summary of the findings of the study **Children's experiences of Disability: A Positive Outlook**<sup>7</sup> said:

*The picture which emerged from this study is a group of disabled children who are devoted to "ordinariness". They took a pragmatic and practical approach towards the management of their impairments, strove to be helpful sisters and brothers, good friends and enthusiastic classmates. In attempting these things they were, for the most part, supported by loving parents and accepting siblings. They also seemed to be well supported by the voluntary agencies they encountered. Support from other services was, however, more patchy.*

*Disabled children encountered barriers in the form of other people's attitudes towards them and the excluding practices of institutions. When it may have been possible for some children to understand or challenge the hurtful attitudes of individuals, it was much more difficult for them to address the barriers within large institutions. Nevertheless, the children maintained a positive outlook and viewed the future with great optimism. Many young people wanted to be able to access the same leisure venues as their non disabled peers.*

Children in Scotland's **Citizen in Partnership** project worked with 50 young people identifying their interests and concerns. These included:

#### Attitudes

- Not being treated like a child
- Talking to me, not my parents
- Being treated the same as everybody else

#### Choice

- About when and where I get respite
- Who helps me get up in the morning

#### Inclusion

- Meeting young people who do not go to my school
- Meeting children and young people without disabilities
- Being part of my community

#### Wider issues

- Going to hospital and how I am treated there
- Being able to vote

The **Audit Commission's review**<sup>8</sup> of services for disabled children and their families began by listening to disabled children. Their findings about the views of disabled children echo what we have already heard from other stories and consultation:

- What matters is being respected and listened to, being able to play and have friends, and feeling safe and comfortable.
- Children also said how painful it was to be left out of ordinary activities that others take for granted.

**Not more but the same**<sup>9</sup> offered the views of disabled children from Black minority ethnic communities in Scotland. Of the nine disabled children and young people interviewed, most wanted to do the same things and enjoy the same access as their non-disabled peers. Some felt adults focused on what they could not do, rather than what they could. Few had friends outwith school or college. Access to culture and faith was not supported in schools, and sometimes discrimination and a lack of knowledge meant access was also denied within the local community.

## Siblings

Siblings of children with disabilities are powerful allies for their brothers and sisters. As part of the same generation (living in the same era) they can relate more closely than adults to children's interests.

However, having a brother or sister with a disability can also impact on the sibling's desire for a normal life. Disturbed nights, disrupted outings, isolation and guilt are just some of the emotions that brothers and sisters of children with additional support needs may face.

Some siblings feel guilt that they don't have the disability but their brother or sister does. They can experience strong emotions about their brother or sister and worry about what the future holds for them. They may get limited time and attention from their parents and feel overlooked by their families, or they may feel that their brother or sister is being over protected. Guilt and resentment can be key emotions when they see their parents struggle and therefore the overall effect on family life is made more difficult.

Most young people are concerned about the opinions of their peers. Siblings of children with disabilities may worry about what their friends might think, and can be bullied and teased by their classmates. Some feel embarrassment when out and about in public.

However, siblings are also very positive about the relationship they have with their brother or sister, and the knowledge and understanding this brings. Information gathered by Down's Syndrome Scotland showed that siblings felt very positive. They felt that:

- Their brother or sister can be fun.
- They themselves have more understanding of other people's disabilities.
- They sometimes have a wider group of friends as a result of their brother or sister's disability.
- They feel closer to their brother or sister.
- They get to know their own strengths.

*'I wanted my brother to go to the same school as I went to.'*

When parents were asked about their concerns about their non-disabled sons and daughters, they highlighted almost exactly the same issues as the siblings themselves.

Siblings often go through many of the same feelings as parents in relation to service provision for the family, but because they are younger find it more difficult to rationalise. They can become angry about the fact that providers do not offer the services that their brother or sister needs. They take on responsibility for their brother or sister's needs not because it is expected of them, but because they love their brother or sister. Siblings need to see that professionals want to support families in order that their lives are more balanced.

## International and national policy context

The **United Nations Convention on the Rights of the Child**<sup>10</sup> incorporates the full range of human rights of all children. The underlying values – or ‘guiding principles’ – of the Convention guide the way each right is fulfilled and respected and serve as a constant reference for the implementation and monitoring of children’s rights. The Convention’s four guiding principles are:

- Non-discrimination (Article 2)
- Best interests of the child (Article 3)
- Survival and development (Article 6)
- Participation (Article 12)

Scottish Ministers have identified expectations and aspirations relevant to all Scotland’s children and young people, applying across agency, service and professional boundaries, and consistent with the principles enshrined in the United Nations Convention on the Rights of the Child:

‘In order to become successful learners, confident individuals, effective contributors and responsible citizens all Scotland’s children and young people need to be:

- **Safe:** Children and young people should be protected from abuse, neglect and harm by others at home, at school and in the community.
- **Nurtured:** Children and young people should live within a supportive family setting, with additional assistance if required, or, where this is not possible, within another caring setting, ensuring a positive and rewarding childhood experience.
- **Healthy:** Children and young people should enjoy the highest attainable standards of physical and mental health, with access to suitable healthcare and support for safe and healthy lifestyle choices.
- **Achieving:** Children and young people should have access to positive learning environments and opportunities to develop their skills, confidence and self esteem to the fullest potential.
- **Active:** Children and young people should be active with opportunities and encouragement to participate in play and recreation, including sport.
- **Respected and Responsible:** Children, young people and their carers should be involved in decisions that affect them, should have their voices heard, and should be encouraged to play an active and responsible role in their communities.

- **Included:** Children, young people and their carers should have access to high quality services, when required, and should be assisted to overcome the social, educational, physical, environmental and economic barriers that create inequality.'

It is against these principles that **all** children's services will be measured. All policy and legislation relating to children is equally relevant to children with learning disabilities and children with autism spectrum disorder.

Part of the work of the Children's Group was mapping existing policy and legislation that impacts on children in Scotland. Policies relating to children's services support the vision of *The same as you?* and offer opportunities to ensure the expectations and aspirations relevant to all Scotland's children and young people include those with learning disabilities and those with autism spectrum disorder.

Recent and ongoing policy and legislative developments in Scotland identify children as a priority and support the delivery of effective integrated working:

Scottish Ministers have agreed a high level vision for children and young people in Scotland:

'... we want them to have ambition for themselves and to be confident individuals, effective contributors, successful learners and responsible citizens. All Scotland's children and young children need to be nurtured, safe, active, healthy, engaged in learning, achieving, included, respected and responsible if we are to achieve our ambition for them.'

- *For Scotland's Children*<sup>11</sup> assumes an approach that has the child at the centre.
- *Our national health – a plan for action, a plan for change*<sup>12</sup> highlighted three priority areas relating to children: health of children; improving child health and children's services; and providing children with equal and easy access to comprehensive and integrated services.
- *Improving Health in Scotland – The Challenge*<sup>13</sup> identifies priority areas relating to early years and teenage transitions.

- *Improving Mental Health and Wellbeing*<sup>14</sup> has a focus on improving the mental health of pupils.
- *The Integrated Strategy for Early Years*<sup>15</sup> sets out a framework for the effective provision of universal and targeted services for children and their families, from pre-birth to age 5. The strategy draws together existing policies for health, education and social care services which are directed at the early years of a child's life and at the parents and families of those children.
- *It's everyone's job to make sure I'm alright*<sup>16</sup> reports on the a review of child protection. It promotes the reduction of abuse or neglect of children, and makes recommendations to improve the services for children who experience abuse or neglect.
- The Additional Support for Learning (Scotland) Act 2004<sup>17</sup> aims to ensure that all children and young people receive the additional support required to meet their individual needs and to help make the most of their education. It also gives parents more say in their child's education.
- The Standards in Schools etc. Act 2000 requires Scottish Ministers to set national priorities in education. These are described later in the report.
- *The Integrated Children's Services Planning Framework*<sup>18</sup> brings together previously separate plans for children's services, school education, children's social work, child health and youth justice. The plans cover services for all children including those with disabilities.
- *Integrated assessment framework*<sup>19</sup> aims to facilitate efficient and effective information sharing and assessment and lead to integrated support for children across all agencies.
- *Health for all Children* (Hall 4) provides guidance on health screening to promote the integrated provision of universal and targeted services for children and families.
- *Children and Young People's Mental Health: A Framework for Promotion Prevention and Care*<sup>20</sup> sets out a range of activities and approaches to support children and young people's mental health and wellbeing.

## Children's Commissioner

Professor Kathleen Marshall took up her appointment as the first Commissioner for Children and Young People in Scotland on 26 April 2004.

The general function of the Commissioner is to promote and safeguard the rights of children and young people and to:

- generate widespread awareness and understanding of the rights of children and young people
- consider and review the adequacy and effectiveness of any law, policy and practice as it relates to the rights of children and young people
- promote best practice by service providers
- commission and undertake research on matters relating to the rights of children and young people.

In addition to this specific focus on children and young people there are also wider policy initiatives relating to areas such as social inclusion and tackling the commitment to eradicate child poverty.

All of these policies provide an opportunity to take account of the needs of children and young people with learning disabilities and autism spectrum disorder, both in relation to the inclusion of people in universal policies and in targeting specific policies relating to particular vulnerabilities and risks. Further details of relevant publications are set out in **Annex C**.

The vision and principles of *The same as you?* are shared in a number of policy documents. The framework for person-centred, integrated services already exist. But children with learning disabilities and with autism spectrum disorder and their families still face barriers throughout the journey from birth to adulthood.

The following chapters look at the strategies relevant to different life stages and effective steps to delivering their aims. However, whilst they relate mainly to statutory agencies and professionals, the importance of community supports throughout an individual's life should not be overlooked.

Research published in 2002<sup>21</sup> concluded that:

'Any review of literature inevitably tends to focus on the strategies that are, or could be, adopted by professionals in health, education and social care. This runs the risk of implying that the actions of professionals are of a higher order of importance than those of other actors.

However, when children themselves are asked what helped them "succeed against the odds", the most frequently mentioned factors are help from members of their extended families, neighbours or informal mentors, and positive peer relationships, rather than the activities of paid professionals. In developing conscious strategies to promote children's resilience, we must be careful not to undervalue these non-professional sources, and more importantly, ensure that our actions do not result in such naturally occurring sources of support being weakened.

The transient involvement of a professional is unlikely to be a good exchange for a lifetime commitment from family, friends or kinfolk.'

What matters most to children with disabilities is ordinary things, and the long term, consistent contribution of their families, community networks and other children.

This report aims to highlight practical steps and good practice in implementing the above policies that will ensure the needs of children with learning disabilities and with autism spectrum disorder are met in mainstream services with specialist support when needed.

It also aims to show that there are few of us who do not have a role in tackling the discrimination and stigma that limits opportunities for children and young people in our society.



SECTION TWO

**A CHILD'S LIFE**

## Chapter 1: Early years

Most children spend the majority of the first four to five years of their lives with parents or close family members. Time spent at play-groups and nurseries leads to natural networks where children come into contact with their peers and parents provide mutual support on the everyday challenges of being a parent.

The experience of people with learning disabilities and with autism spectrum disorder can be quite different, whether they are faced by barriers to them as children or as parents with disabilities. This chapter highlights some of these differences and offers some suggestions on practical steps to removing these barriers. Whilst health services are relevant to all stages of life, this section looks more closely at meeting health needs, and the importance of providing the right supports from outset.

*The same as you?* identified some key supports for children and families where a child is born with a learning disability.

When parents are told that their newborn baby (or child) has a condition which includes learning disabilities, their lives are changed forever. Their child may still be the greatest source of joy and inspiration and bring pleasure and pride to them, their family and friends. However, their world will not be as it was. They may face many challenges, some of which may frustrate or exhaust them.

If a child is born with a learning disability or does not reach expected early developmental milestones families need:

- information, practical help and emotional support from knowledgeable professionals;
- access to ongoing advice, local child care, paediatric and child health services which can meet their child's needs;
- therapy services included with ordinary children's services;
- programmes which teach parents and carers in nurseries, schools and respite settings how best to help each child develop; and
- early information, advice and options for pre-school and primary education.

*(The same as you? 2000 p 79)*

These supports are equally important to families with children with autism spectrum disorder. Many of these mainstream services are valued by most families in the early years of parenthood.

Some people with learning disabilities may go on to choose to become parents. As with other parents, they will need a range of support and help from their family members and other agencies. They too benefit from training and support to develop parenting skills. Legislation and policy state that children should, as far as possible, be supported to stay at home with their natural parents. It is equally important in this context that people with learning disabilities are not discriminated against on account of their disability.

Challenging stigma and promoting social inclusion from the earliest years will give all children the opportunity to develop and reach their full potential. Getting support and services right from the start will reduce the need for corrective action later in life that is more costly in both human and financial terms.

## Barriers and supports

### Information

Most of us benefit from support from family, friends and our communities. When a child is born, a range of support is provided, from mainstream services such as health visitors and the provision of a free part-time pre-school place for every three and four year old whose parents wish this.

Families have stressed the importance of information that helps them understand their child's disability. For many families, the first experience of disability will be their with their own child. They need support to explore values and beliefs, to know their rights, and to inform them of choices they will have to make about their child's future:

*'If you know nothing you fear the worst'.*

*'Information-wise, parents don't need a lot, we just need good quality information and some people who understand.'*

Voluntary sector organisations provide families with a range of disability specific information as well as information on wider issues that impact on their lives. **Annex D** lists some useful contacts for those with an interest in

learning disabilities and autism spectrum disorder. As a national centre of excellence, the Scottish Consortium for Learning Disability (SCLD) provides information and training on good practice in making *The same as you?* happen.

Recognising the specific difficulties faced by families with children with autism spectrum disorder, the Scottish Executive is currently funding two complementary projects that will provide information through both health and educational settings when someone is diagnosed with autism spectrum disorder (**See Annex D**).

### **Working together**

Some families need more targeted support. However, some of the stories we gathered described a lack of partnership with families and a struggle to access services:

*‘Service land emerged and overtook our lives.’*

*‘We want Jill to have the same lifestyle as every parent wishes for his or her child, but we have to fight for everything.’*

Involving families from the outset builds trust and delivers better outcomes for everyone.

*‘The best way to support families is to first of all ask them what they need or want.’*

There are a number of initiatives that assist the delivery of the policies summarised in Section 1. *Sure Start Scotland*<sup>22</sup>, the National Health Demonstration Project *Starting Well*<sup>23</sup>, and other targeted initiatives provide a range of additional services to support vulnerable families such as centre-based support, childcare, outreach and home visiting services, and various forms of parenting support.

Pre-School Assessment Teams provide a multi-agency assessment process for children from birth to age five to identify supports required. In Fife, a multi-agency pre-school Community Team, with the involvement of keyworkers, organises meetings with families at times and places to suit their needs. Numerous research studies report that parents want a single point of contact with services and an effective named person to help them get the services they need. Keyworker services have been provided from a number of agencies for several years. However, research on care co-ordination and keyworker services for disabled children in the UK found that the coverage of schemes was patchy and under-developed<sup>24</sup>. Local area co-ordination builds on this and is developing across learning disability services in Scotland. This is discussed more fully in Section 3.

## Attitudes

One of the first barriers the family of a child with a disability faces is attitude and stigma:

*'I have come across many individuals who do not value my son's life.'*

Families described some of the things that don't help them:

- Feeling that they are always fighting and that there is no real understanding
- Presuming that a young person doesn't understand because they are non-verbal communicators
- Thinking one child is identical to all children with a particular label, for example a child with Down's syndrome:

People who think that, because James doesn't speak much to them, he doesn't understand what is going on or what is being said.

People who make assumptions about what James's life will look like. Like the paediatrician who assumed that James would go to a 'special needs' play-scheme, even though he goes to mainstream school and takes part in all mainstream activities.

School staff who are taken aback when I raise the issue of academic work and achievement.

Teaching staff who see him as the responsibility of the learning support staff and not as part of the class, who are happy that he – and the other children with disabilities – exists in a *parallel universe*.

*Education staff that persist in putting forward 'special' and segregated activities when we have made it clear that James will take part in mainstream activities only.*

*Youth group leaders who think that one child with Down's syndrome is identical to every other and look upon James as a liability and not a valuable addition to the troupe.*

Including children with disabilities from the earliest years goes some way to addressing this, and brings about a better understanding of disability. It has benefits for other children too.

People see Peter first and foremost as a wee boy and not as a bag of problems. A good example is the play-scheme Peter goes to, where the staff appreciate his sense of fun and energy, value the added dimension he gives to their work, and understand that it brings benefits to the other children who take part to have a child with disabilities among them.

## **Making choices**

Parents have different views about mainstream and specialist educational provision for their children. What is right for one child may not suit another. That is why being offered real choice is important. Parents need to feel that a decision about their three year old child's education does not confine them to that route throughout their school years, and that they have a right to change their minds as their son or daughter develops.

## **Pre-school nursery**

*The same as you?* emphasised the importance of services working together to make sure moving from one stage of a person's life to another is planned for and managed as smoothly as possible. Children with learning disabilities and autism spectrum disorder experience the same transitions as other children – starting nursery, from nursery to school, primary to secondary and leaving school. These children may also experience the transition from, as well as within special and mainstream nursery and school provision.

*The same as you?* principles say that children should have services which take account of their age, abilities, and other needs and not be picked on or treated differently from others. It is much easier for children to be part of the community they live in if they share transitions in their lives with their local peers. Following the same path at the same time as others allows them to be fully included.

Whilst views on mainstream and specialist provision vary, what matters is that parents have real choice for their children, and that access to mainstream education is not limited by the attitudes of others or the right supports being available. Many parents will be thinking about disability for the first time, and may not have any views on the benefits or disadvantages of mainstream or specialist education. Contact with other children and families who have this experience will help inform their decisions.

The first story describes a child's successful transition from specialist to mainstream nursery:

*Beth first went to nursery when she was just 2; this was a special needs nursery. By all accounts she was very happy there and coped well with the routine. During this period it was suggested that we consider integrating Beth into a mainstream nursery, as she would benefit from the inclusion with other mainstream children. This was done over a period of a few months, starting one day a week. Beth adapted to this so well that the transfer to full-time took place within a couple of months and she remained there taking one extra pre-school year until her transfer to primary.*

The family in this next story felt the child's needs were best met in a specialist environment:

*When Craig was about 3 he started at the nursery of a school for children with special needs. This was a fantastic environment to stimulate him and he was given a lot more attention than I could ever have given him at home. He had regular physiotherapy and speech therapy, and while progress was still very slow, he was responding to people well and enjoyed the attention. He was a very content little boy, although prone to tantrums, but only when he was at home. Despite his limited understanding, Craig knew that Mum and Dad were the people he could take any frustrations out on.*

The following story shows the important factors mainstream education provided for their son:

*David joined mainstream nursery despite us being advised against it by psychologists. He had always been special before but there he was, just David who was capable of taking part in life, was able to make and maintain friendships, and be a regular 'wee' boy ...*

Increasingly children with learning disabilities go to their local play-group or nursery at three years and nursery at four, like other children, although children with profound and multiple disabilities are most likely to attend a special/separate educational establishment. Some also attend child and family centres.

The stories gathered for the report also suggested that children with autism often spend their pre-school years and beyond in special provision.

### **Transition to primary school**

One of the biggest transitions in anyone's life is starting school. Most people have some memory of their child's if not their own first day at school. It is at this point that the path of children with disabilities at the moment may diverge from the path of their peers.

The following is an example of a successful transition from nursery to school:

*Frances adapted well to her change of learning assistant at nursery and responded well to her. Such a good bond developed between them that the learning assistant now works with Frances in primary one. Having spent a year making friends the transitions to school was easy. Her class teacher was able to meet her in the nursery setting and also meet and talk to her Mum. She was able along with the learning assistant to do the Sign-a-long course in advance of Frances starting full time. She was also able to draw up an individual learning plan in liaison with nursery staff which helped with the transition.*

The age at which a child starts school has an impact on how well they adapt to school life. Anecdotally parents are not aware that children born between September and February can start school after their fifth birthday rather than when they are four. Research evidence from around the world shows that for children this age it is much better in the long run to start later, especially for boys. In a number of European countries, children start at 6 years allowing the not so able to be ready to start and the more able show no detrimental signs because they have waited. In Scotland this still has the stigma of 'keeping the child back'. Parents may choose to avoid this option believing a later start will reflect badly on their child. A major review of the 3 to 18 curriculum is underway in Scotland, and Ministers have commissioned a report that will identify what lessons Scotland can learn from the delivery of early years education around the world.

## Health

### **Scottish Health Survey 2003<sup>25</sup>**

The 2003 survey's chapter on children identified the following issues:

- More than nine in ten children had 'very good' or 'good' self-assessed general health.
- 23% of boys and 14% of girls had a long-standing illness. Almost twice as many boys as girls had a limiting long-standing illness (9% versus 5%). The most common types of illness reported for boys were of the respiratory system followed by mental, behavioural and personality disorders. The most common illnesses reported for girls were of the respiratory system followed by skin complaints.
- Just under one in ten (9%) children had had an episode of acute sickness in the two weeks preceding the interview. Most episodes of acute sickness were short (1-3 days).
- Behavioural problems in children aged 4-12 (as measured by the Strengths and Difficulties Questionnaire) were more common in boys (10%) than girls (7%).
- Around one-fifth of boys (20%) and girls (17%) were taking at least one prescribed medication. The most commonly taken medicines were for respiratory and skin complaints.
- Nearly all children aged 6 and over had attended a dentist at some point.

The picture for children with learning disabilities and children with autism spectrum disorder can be quite different. Many children with learning disabilities and children with autism spectrum disorder are fit and healthy. However, it is also the case that the health needs of these children often go unrecognised.

A Health Needs Assessment Report<sup>26</sup> on people with learning disabilities in Scotland described the higher level of health needs people with learning disabilities experience, and how these differ from the rest of the population. About 20-25% of children and young people with learning disabilities have epilepsy, increasing to over 50% of children with profound and multiple learning disabilities. Children with learning disabilities are at increased risk of visual and hearing impairment therefore early detection and correction is

important. A wide range of mental ill-health and problem behaviours are experienced, and some genetic conditions result in thyroid dysfunction, celiac disease, ear nose and throat problems and obstructive sleep apnoea. The *ASD Health Needs Assessment* also described co-morbid conditions for people with autism spectrum disorder, including clinical depression, anxiety, epilepsy, sensory sensitivity, and dietary problems.

Children with learning disabilities and autism spectrum disorder can access the same health services as everyone else, with some specialist services to support them and their families. Organisational arrangements for these services, and the age range covered varies across Scotland. The factors that affect access to services for these families include communication needs, problem behaviours, multiple co-existing needs and low expectations of services due to previous bad experiences.

High rates of accidents and injuries occur amongst children with learning disabilities. This may be due to increased rates of epilepsy, mobility and sensory impairments and for some people problem behaviour which can result in self-injury.

A tiered approach to care is set out in guidance for Community Health Partnerships on *Improving the health and wellbeing of people with learning disability and/or autistic spectrum disorder*.<sup>27</sup>

Tier 0	Community resources and supports, housing and support packages, education and learning, employment, public health initiatives, and policy developments	Learning Disability/ASD Partnership and CHPs
Tier 1	Primary health care services, directly accessed services, and their supporting services and paid and family carers	All CHPs
Tier 2	Generic community and secondary (outpatient, inpatient and tertiary) health services accessed via primary health care services, and their supporting services and paid and family carers	All CHPs with Acute Divisions

Tier 3	Community learning disability/ASD and child health services provided by local authorities, NHSScotland, and the independent sector, and paid and family carers in support of these	All CHPs (jointly managed and/or with delegated responsibility as appropriate)
Tier 4	Regional/area – specialist learning disability/ASD services provided by local authorities, NHSScotland, and the independent sector, and paid and family carers in support of these.	Lead CHP

This tiered approach aims to ensure the health needs of people with learning disabilities and with autism spectrum disorder are addressed in general services in the same way as the rest of the population, with onward referral to specialist services for those who need them. Accessible primary care services are therefore vital. SCLD and NHS Education for Scotland have taken forward specific initiatives to address this.

## Play

*'Play is what children do in their free time, when not being directed by adults.'*

*'Play is freely chosen, personally directed, intrinsically motivated and engaging.'*<sup>28</sup>

Policy and guidance suggests that all children should be afforded the opportunity to the 'best possible start in life'. Play is a fundamental and important part of a child's development. Play helps children's social skills, physical activity, motor skills and co-ordination, emotional development, intellectual skills and creativity. Positive experience of play, therefore, significantly aids a child's development towards becoming a fulfilled and rounded citizen.

Children with learning disabilities and with autism spectrum disorder are all too often denied play opportunities, further excluding and disabling them in society. Parents may need advice and support to enable them to understand the benefits of play for their child.

*Brad is 18 and was diagnosed with Lissencephaly when he was 8 months old. He has complex needs and can't do much for himself. He can sit up on his own and reach out for things, but with poor dexterity.*

*When Brad was about 18 months, a home teacher came to the house of his childminder and discussed ways to encourage play with him. This was useful for a couple of reasons. Firstly, to stimulate Brad who was not exploring things on his own like other toddlers. Secondly, it taught my childminder and me how to play with him. As a first time mother everything was new, but as the young mother of a disabled child, things were even more daunting and I didn't know where to start.*

The importance of play increases as children develop, especially as they become more independent and spend more time in the company of friends. Chapter 2 looks in more detail at play during school years.

## **Person-centred supports from the early years – suggestions for good practice**

No matter what your involvement is in providing services and support for children with learning disabilities and autism spectrum disorder, these good practice guidelines will help you to identify practices that focus on the child's interests and help build trust and good working relationships between families and professionals.

### **Information, training and awareness**

Information, training and awareness needs are identified and acted upon

#### **Good practice**

- Parents know their rights and have adequate up to date, accessible information about what might work for their child
- Funding is available for empowerment courses for parents
- Information is available about the child's disability and who to contact for advice and support
- Information leaflets are provided for siblings (gathered from various organisations, i.e. not necessarily creating new ones – see Annex D)
- Training is considered for siblings on how to handle 'bullying' specifically related to having a brother or sister with additional support needs

- Training on parenting skills is put in place for people with learning disabilities and autism spectrum disorder who want to become parents. Ongoing support is needed for those who are parents already and those who become parents in future
- Regular 'informal meetings' are held with parents, where possible in a place, and at a time, convenient to families
- Training and awareness needs are identified for people coming into contact with the child, including playgroup staff, their managers, and family members
- Staff learn to communicate with the child, and establish a good relationship between nursery/school and family
- Everyone understands inclusion and is committed to including the child
- Other pupils are encouraged to become actively involved in including this child as part of their school community.

### Planning

Planning is done jointly with all relevant parties, including family members.

### Good practice

- People who are involved in planning for the child's future are identified as early as possible
- Families discuss the support they need and all parties agree how planning will be done in partnership – LISTEN to what families WANT and NEED
- Planning is person-centred. Action plans are created, with people taking on individual jobs so parents can become 'Mum' or 'Dad' again, not support co-ordinators
- Children are supported to take part in planning meetings. Early involvement of the child helps with major decisions
- Individual learning plans are jointly prepared by nursery, school, support staff and family members
- Siblings are involved in future plans for their brother or sister
- Teaching and other professionals take time to get to know the child by home visits or visiting the nursery.

### Supports\*

Support for family members and staff who provide services is in place and regularly reviewed

### Good practice

- Support is provided that allows families to be parents and NOT co-ordinators of services. Families are put in contact with a local area co-ordinator or similar
- The need for an advocate is considered and professionals are aware of the role of the advocate
- The need for respite or short breaks is discussed with the family – this can serve as a support to manage stress
- Respite/support is provided to allow parents to give 'individual' quality time to siblings. Siblings are involved in respite support provision that is offered
- Direct payments are discussed and made available to families who are entitled to support
- Siblings support groups that are fun and informal are organised, allowing children opportunities to be with other children in similar situations
- The supports that the child and the teacher need are identified in advance of the child starting nursery/ school and put in place on day one
- Support needs are regularly reviewed.
- Supports enable all parties to identify and agree outcomes

\*Local area co-ordination, access to advocacy services, respite services, and direct payments are discussed more fully in Section 3.



## CHAPTER 2

# SCHOOL YEARS

Children with learning disabilities and autism spectrum disorder should have the opportunity to develop and make the most of their abilities. This applies not only to formal education but also to life outwith school and relationships with others. Our health and wellbeing, physical and mental, has a major impact on our ability to participate in all aspects of life.

This chapter looks at the support children, families and front-line staff need during school years. We suggest a number of practical steps that help families to have real choice and give children the opportunity to have a full life.

The most important rights of children and young people with Special Educational Needs (SEN) are the right to an appropriate education and the right to be fully integrated into the community to which they belong when they are adults. Inclusion in ordinary schools or, segregation into special classes or schools, is only defensible if it facilitates these two rights (Hornby).

The Scottish Executive's current policy aims to increase social inclusion but accepts a need for special schools. Every child should have full-time education that meets their needs, and support to make the most of the learning opportunities available.

Special schools provide for a smaller number of children whose needs are too great for most ordinary schools to meet, such as those with profound and multiple disabilities. Some profoundly disabled children manage well in mainstream classrooms with a lot of support. The Scottish Executive has issued guidance for staff working with children in educational settings on providing intimate care for children and young people with disabilities. The most important consideration is that the education should be good quality and meet the child's needs, not least their wish to be included and have friends.

*The same as you? 2000 pp. 79-80*

*The same as you?* principles and education policy are clear that wherever children live they should have an equal opportunity to be in mainstream education from nursery upwards. What matters is that there is real choice that is not limited by a lack of understanding of inclusion. People also need to be assured of the right supports to make that choice a sustainable one. There is a need for specialist and mainstream services to work together to provide a seamless service with good information exchange between early years, primary and secondary education. A number of policy developments work towards this.

## Making choices

Decisions about which school a child attends for their most formative years cannot be taken lightly. At this stage, families need support, with information about the options available. There are numerous factors that affect this decision when the child has a learning disability or autism spectrum disorder.

## Starting school

The National Priorities in Education<sup>29</sup> are:

- achievement and attainment
- Framework for learning
- inclusion and equality
- values and citizenship
- learning for life

‘Inclusion and equality’ aims to help every child to benefit from education, with particular regard to pupils with disabilities and additional support needs. The overarching context is one of schools developing their capacity to provide for the full range of children and young people within education. The most important principle is to meet the needs of the individual child in an appropriate setting, whether this be mainstream, specialised or mixed.

Despite the aims of policies in social inclusion and in education, a number of the stories gathered suggested that families still experience a lack of real choice for their children:

*Our daughter started mainstream primary school in September 2001, something we should have been able to take for granted. Unfortunately, this was only after many meetings with educational psychologists, teachers, access officers, speech therapists, physiotherapists, nursery staff and others, and the traumatic effect of an appeal against a placement request.*

Since publication of *The same as you?* there have been significant developments in education policy in Scotland, most recently with the Additional Support for Learning (Scotland) Act 2004. This new framework for supporting children and young people in their school education imposes a range of duties on education authorities and provides for the rights of young people and families:

**Education authorities:**

- must make adequate and efficient provision for each child or young person with additional support needs for whose education they are responsible
- must also provide appropriate additional support for disabled children under 3 where the child has been referred by a health authority and has additional support needs arising from the disability
- must make arrangements to identify additional support needs
- must, when establishing an individual's additional support needs or when determining the provision of support to be made, or when establishing whether a co-ordinated support plan is needed, take account of advice and information or views from others, including other agencies and the child or young person and their parents.
- must publish information about provision for identifying and addressing additional support needs
- must provide those children or young people who need it with a co-ordinated support plan and keep this under regular review
- must provide independent and free mediation services for all parents of children with additional support needs and publish information on these services
- must request, and take account of, information and advice from appropriate agencies and other persons likely to support the child when he/she leaves school. This must all be done at least 12 months prior to the expected school leaving date
- must at least 6 months before the child leaves school provide information to whichever agencies will be responsible for supporting the young person once they leave school, including Careers Scotland, Further Education Colleges and Higher Education Institutions, if the young person agrees. This information could include any provision the local authority may make for example through social work or housing when the child leaves school.

**Parents will have new rights to:**

- request the education authority to find out whether their child has additional support needs
- request the education authority to find out whether their child needs a co-ordinated support plan or to review an existing plan
- request a specific type(s) of assessment and/or examination
- request the use of mediation services and dispute resolution services

- make a placing request to an independent special school if their child has additional support needs
- be informed of the outcome of these requests and any applicable rights of appeal
- receive a copy of the co-ordinated support plan or, if not eligible for a plan, receive advice and information about their child's additional support needs
- have their views taken into account and noted in the co-ordinated support plan
- make a reference to the new Additional Support Needs Tribunals for Scotland on matters relating to co-ordinated support plans
- have a supporter or representative with them at any meeting with the school or education authority and at a tribunal hearings.

Young people will also have these rights on their own behalf.

In addition, education authorities will be able to help other children and young people with additional support needs who are not in education authority schools, for example those being educated at home or who are receiving private education. This is not a duty, but parents of these children will have a right to request assessment of their child's needs and the authority may provide advice, information and help.

The Act also introduces a new duty on other bodies, such as NHS Boards, as an appropriate agency, to help education authorities to identify and support children's and young people's learning needs.

It is right that families have choice. Children are individuals and the type of support they are given should be based on their individual health, educational and social needs.

We heard of good experiences in both mainstream and special schools. Some parents who had moved their child to mainstream felt special education offered no challenge, little stimulus, and placed little emphasis on work placements. Some believe it results in unnecessary separation from peers in mainstream.

The benefits of special schools included: access to specialist therapies; staff who understood the child's needs and who are trained in additional support needs; a specially adapted curriculum; and a better response to communication difficulties.

Recent research<sup>30</sup> into mainstreaming pupils with special educational needs suggests that there have been substantial efforts to provide for children with moderate learning difficulties, and those with social, emotional and behavioural difficulties, visual or hearing impairments and autistic spectrum disorders in mainstream settings; and indeed that this is their initial placement.

The survey also found that the age profile of the special school population is changing, and that the majority of children and young people currently attending free-standing special schools are of secondary school age. Whilst there are no clear conclusions to be made about the benefits of mainstream versus specialist educations, it does highlight the opposing views of parents about the best provision for their child.

The following stories collected for this report describe these differing views.

*Our youngest daughter Elsa received a label of 'severe autism' just before her third birthday. School for Elsa was to be within a Language and Community Facility (there was no alternative on offer), along with approximately 16 other children all having varying degrees of autism or language and behavioural difficulties. The emphasis was on offering Elsa a low stimulus, autistic specific curriculum. Inclusion for me is clearly the way forward. As Elsa started at school I embarked on an 8 month course designed for parents of children with disability and self advocates. Among many other things, I learnt about the values of inclusive education and the importance of community. I began to realise how different life as an adult for Elsa could be if she were educated alongside her typical peers compared with the path she was already travelling. I requested a mainstream placement for Elsa at her local school, believing this would reap benefits for our whole family in the years to come. It was certainly challenging and took over 2 years of battling with the authorities, legal systems and more fundamentally overcoming many attitudinal barriers. Looking at Elsa now, we see a very different girl in every way. Her language, social behaviours and even posture have altered. At age 10 she is now finally beginning to develop natural friendships for herself. I remember once being told in the early years 'people with autism don't need friends'. Goodness how wrong they were. Everyone needs a network of family and friends, just as everyone needs to be valued and to play their part in society. As a*

*family we still have to help facilitate and develop these new relationships for Elsa, but she is clearly becoming more able to do so for herself and growing in confidence as a person daily as a result.*

This story emphasises how the principles set out in *The same as you?* apply to life at and beyond school.

- The Individual is valued
- She is asked and encouraged to contribute to the community she lives in
- She is not picked on or treated differently from others
- She is treated as an individual
- She and her family are asked about the services they need and are involved in making choices about what they want
- Support helps her do everything she is able to
- She is using the same local services as everyone else
- She is benefiting from specialist services and
- She has services that take account of her age, abilities, and other needs.

Some children have considerable support needs, and families feel specialist provision is more able to respond to their needs:

*Our son Jack is 10 and has Lowe syndrome. He has profound and multiple learning difficulties, registered blind but wears contact lenses, has autism spectrum disorder, no speech, is doubly incontinent, epileptic, has low muscle tone which delays his gross and fine motor control, he is growth restricted and has an ongoing kidney disorder for which he has to take medication three times a day. That sounds grim reading and it is, but does nothing to describe the happy, beautiful wee boy our son is. Jack attends a special school – this is now his fifth year there. He also has two healthy sisters, aged 11 and 3. We cannot overstate how successful this placement has been for him or how much we admire, respect and value the staff and ethos of the school. The school works very much in partnership with the parents. There is no sense of dictatorship. The targets that are set annually for Jack are realistic and give him real opportunities to experience success. Every child at the school is treasured and each child is given the time, space and experienced understanding they need to function successfully at school.*

The main contributory factors to a positive experience of education for children with learning disabilities are attitudes, careful and early planning for transitions, and involving individuals and family members from the outset. This head teacher's story demonstrates that positive attitude:

*Our inclusion policy is to take all: just send them along! How can you do anything else? You can't judge by diagnosis. We have about 30 children with autism spectrum disorder out of 570 children in the school. All 30 are different. There's not one thing that is common to all of them. They all behave and react differently they have all got different home backgrounds. So we take a child centred approach to all the children in the school, regardless of their label. We have 72 children in the school with additional support needs likely to last the length of their primary school career, including types of cerebral palsy, Down's syndrome, ADHD and Asperger's syndrome. Over 50 children use psychological services. Many of our children are swans; 'syndrome without a name!'.*

There are differing mixes of mainstream and specialist provision, such as a special unit on a school campus, or part time placements in mainstream schools. These may allow children access to both specialist and mainstream, but the Group was not aware of any evidence of the outcomes for children. It is important to consider the impact of segregated provision on perceptions about a child's ability to participate in wider mainstream activities.

### **Transition from primary to secondary**

For all children, the transition from primary to secondary school can be daunting, but the experience is generally shared with a group of friends at the same stage of their lives. For children with learning disabilities and with autism spectrum disorder, this is often a time when they are separated from their classmates. Special units attached to high schools are sometimes provided for young people who have never been in special provision before, because this is the only means of providing appropriate supports.

Young people with learning disabilities often spend part of their week in special provision (unit or school) and part of a week in mainstream high school usually for subjects such as music, PE, drama or art. Young people may be benefiting from specialist social, health and educational services while attending the special provision. However, the availability of these facilities in mainstream high school classes would give a clearer message that the person is valued and not treated differently. Another concern about this part time situation is that it may lead to the lower expectations for the young person.

Raising expectations is often achieved by hearing about successes. An example of a successful transition from primary to secondary highlighted the following steps:

- Good channels of communication with all those involved in the transition.
- A planned programme to raise staff awareness of the young person's needs, and to provide the appropriate staff development.
- Support structures within and beyond the secondary school.

An example of what planning and preparation can involve on an individual basis is given below:

### **Primary to secondary transition: an example of good practice**

- In-service support by Down's Syndrome Scotland to which parents, staff from school and representatives from the Network Support Team were invited; regular review meetings to discuss Euan's particular needs and determine additional support needs in terms of resources and personnel.
- Additional familiarisation visits to high school for Euan; additional visits to the primary school by the main auxiliary support person; a Network Support Teacher (NST) identified as the main support person; NST arranging visit to primary school to work with Euan; NST arranging times for consultation with parents to discuss information to be included in Euan's communication passport.
- Primary school staff regarding Euan's development in terms of the elaborated curriculum. IEP target setting also discussed. Staff at school considering teaching and learning approaches, appropriate curriculum and resources; educational psychologist monitoring and review progress.
- Down's Syndrome Scotland invited to speak with Euan's subject teachers, members of the Support for Learning Department, including all auxiliary staff. Members of the senior management team also attended.
- Organising Euan's timetable to include 1 to 1 teaching support by Support for Learning (SFL) Department. Emphasis on developing communication and orientation skills. It was agreed that the number of subject classes attended by Euan should be increased gradually throughout the session, subject to regular review of his progress.

- Initial consultation with each of Euan's subject teachers to discuss his current levels of attainment, appropriate teaching and learning approaches, resources and planning and monitoring procedures.
- Setting IEP targets – SFL Department following consultation with staff.
- Distributing Euan's PSD targets to all staff.
- Timetabling auxiliary support. Liaising with 6th year students in organisation of interval and lunchtime supervision.
- Follow up visit by Down's Syndrome Scotland. PSD target evaluation sheet distributed to all teaching and auxiliary staff Maths and Language and Communication targets reviewed and next targets formalised.
- Post Placement review.
- SFL Department meet with parents to set PSD targets for both school and home.

The outcome of this thorough planning and preparation for this particular individual was that the young person settled well at high school. The head teacher was in no doubt that the Support for Learning Department must remain pivotal in supporting both the pupil and the teaching staff. The recognised challenge for the future is to ensure that the appropriate levels of support, both in terms of personnel and learning environment, are in place to enable the young person to develop the skills necessary for independent living.

## Planning and working together

### Community Schools

When Integrated (then New) Community Schools approach was introduced in 1998, it had the twin aims of promoting social inclusion and raising educational standards in Scotland, it was also intended that all schools would become Integrated Community Schools by 2007.<sup>31</sup> This approach requires teachers, social workers, family workers and health personnel to work together to develop common objectives and goals centred on the needs of children at school and on families. This is essential to secure good outcomes, not only for children's education, but also for their social welfare, their health, and the well being of the community where they live.

Key Findings from the *National Evaluation of the New Community Schools (NCS) Pilot Programme in Scotland*<sup>32</sup> found that the main achievements reported for the Phase 1 pilot were:

- greater emphasis on multi-agency/multidisciplinary approaches and procedures
- increased provision and support for vulnerable children and families improved pupil outcomes,
- increased community and/or parent and family engagement
- a wide range of new activities, including curricular developments and out of school care/learning
- success areas in particular projects, especially in all aspects of health. Examples included curricular developments in mental health, personal social development, alternatives to exclusion, healthy eating.

Factors that contributed to achievements were commitment to NCS concept, support from other agencies, team working, staff development and clear management structures.

Factors that hindered pilot projects included a lack of clarity and commitment between partners, competing priorities, overly complex management arrangements and professional barriers. Difficulties with bringing staff from different agencies together were reported, from practical issues such as scheduling meetings to differences in professional cultures.

Similar issues were also identified in *The Sum of Its Parts? The Development of Integrated Community Schools in Scotland*<sup>33</sup> a report by HMle in partnership with the Social Work Services Inspectorate and the Health Improvement Strategy Division in the Scottish Executive (SE) Health Department.

In February 2006 the SE Education Department and SE Health Department issued guidance to clarify the roles of local authorities and schools in delivering integrated children's services. NHS HDL (2006) 5<sup>34</sup> confirmed the continued role of all NHS services in supporting a revised objective which states:

*'By 2007 every school in Scotland will participate in delivering integrated children's services.'*

A Scottish Health Promoting Schools Unit has been established and there is a commitment to focus on some of the most vulnerable children and young people in Scotland. Effective health promotion can only take place through health promotion working at all levels and with the engagement of local communities. *Improving Health in Scotland – The Challenge* recognises that schools are uniquely placed to play a vital role in promoting good health. The Scottish Executive has set the goal that all schools should be Health Promoting Schools by 2007.

The continued development of *Schools within an integrated children's services framework and Health Promoting Schools* provides real opportunities to address the needs of children and young people with learning disabilities and with autism spectrum disorder<sup>35</sup>.

### **Integrated children's services**

Local authorities, NHS Boards, police forces, youth justice services, community and voluntary groups are expected to work together to ensure effective integrated children's services which deliver improved outcomes for all children and young people, including those with learning and other disabilities. The views of children, young people and parents should be integral to the planning and delivery of these services. The Executive and its local partners are driving forward an ambitious agenda to deliver these objectives through integrated children's services plans (which bring together previously separate plans for children's services, school education, children's social work, child health and youth justice), a new quality improvement framework, joint inspections, integrated assessment and information sharing and development of the children's services workforce.

The development of integrated planning and assessment arrangements across local authorities, health and other agencies should ensure policies for additional support needs are compatible with those for vulnerable children and children in need.

Planning for learning is an ongoing process subject to continuous review, through pre-school, school and beyond into lifelong learning. Most children and young people who require additional support will have their learning needs met by day-to-day classroom practice. More formal planning arrangements may be required where additional support is needed from other education services and other appropriate agencies.

The Additional Support for Learning Act will introduce a co-ordinated support plan which will be required for those children and young people whose need for additional support arises from enduring complex or multiple factors, and who need services from a number of agencies as well as from education. The co-ordinated support plan is a strategic statutory planning document to co-ordinate the support required to help children and young people achieve specific educational objectives.

The duties on other agencies to assist education authorities meet their duties under the Additional Support for Learning Act and in relation to co-ordinated support plans can help the development of an integrated approach to the provision of school education, family support and health services.

### Barriers and supports

These developments, will hopefully overcome the sense that families feel they are not being listened to, and are seen as competing with rather than allies with professionals.

*The other thing that has been extremely hard over this time has been the lack of partnership working. It has been apparent with all our children but especially Alex how little professionals listen to families and will not work with us as equals given our expertise. Why then should we acknowledge their ideas when we aren't afforded the same courtesy? It is this lost opportunity to work together for Alex's good that saddens us.*

Sometimes the breakdown in relationships is between professionals or agencies. Partnership with parents can resolve some of these difficulties:

*We see psychologists as a resource and support to both parents and school staff, often able to mediate. On an occasion when staff were not willing to follow the psychologist's advice, partnership with parents was useful in changing their minds. Open equal partnerships worked well when established.*

Whilst education authorities have perhaps the biggest influence on a child's development during the school years, the importance of agencies working well together has a major impact on education authorities' ability to support inclusion, as the following story demonstrates:

*There is a real problem with funding responses to the presumption of inclusion. Schools are quite properly taking in more diverse children with health and social work needs. However whilst education have responded brilliantly to these new demands, Health Boards in particular don't seem to have responded fully to this policy change. For example, if a child is assessed by an Occupational Therapist (OT) as needing a hoist, wheelchair, nappies and nappy disposal, special spoons, or basically anything for their physical wellbeing, education have to pay for these health aids. This doesn't seem right. Also, because we only need a tiny number of aids it is far more expensive for us to buy them than it would be for the Health Board to buy in bulk e.g. we have to buy a bendy spoon for one child: the spoon costs £7.50 plus £25 carriage.*

One of the biggest barriers for people with learning disabilities of all ages is the attitude of other people, a lack of focus on ability rather than disability, resulting in a lack of aspiration. Tackling stigma and attitude is a long term process, and SCLD has a leading role in this.

As part of SCLD's public education programme they formed a Schools Group. The group brought together people with learning disabilities, family carers and professionals who had an interest in changing attitudes towards learning disability in schools. The group were also keen to promote positive images and messages about inclusive schooling.

To mark Learning Disability Week 2003 the group ran a competition among some Scottish schools to design a poster celebrating the inclusion of children and young people with learning disabilities within all parts of mainstream schools. The winning design came from merging the ideas of 2 first year pupils from St Ninian's High School in Glasgow. This then became the Learning Disability Week poster for that campaign.

Other groups and organisations have done work with schools to challenge children and young people about to think about learning disability and disability issues in different ways.

For instance Key Housing Associations' Glasgow Tenant's Advisory Group did some talks to assemblies within Glasgow schools. They've also designed their own changing attitudes poster and postcard for displaying in schools.

Previously ENABLE Scotland have been involved in similar work. Their anti-bullying work, included adults with learning disabilities talking to school children about their experiences, producing post cards and also a video about the effect of bullying.

Project Ability (a developmental arts organisation promoting equality of access to the arts) in 2003 ran some Christmas card making workshops for Glasgow schoolchildren. These workshops were facilitated by Art Trek (a co-operative of artists with disabilities) with the aim of raising awareness of learning disability among children in a fun and interactive way.

Playback are another organisation working to change attitudes towards physical disability in particular, among children and young people. They have a number of training and video resources which can be used by teachers to discuss issues facing disabled children and young people.

People First (Scotland) has also done a lot of work, taking anti-harassment workshops into schools. This helps children understand the harassment that people with learning disabilities face. It also helps children overcome any prejudices they may have.

A fundamental approach to successful inclusion is to see the child as an individual, as this head teacher found:

*Eight years ago, we had our first child with Down's syndrome in the school. We made the mistake in the first two months of "trying to teach a child with Down's syndrome". We forgot there was a wee girl in there, and it was all deficit models. We thought "start again", look at the child as a learner, let's see what she can do and at the support she then needs. Everything fell into place, and staff stress levels went down enormously.*

### **Supports for children and families**

Planning, preparation and delivery of services should build around the child and his or her support needs. The desired outcome is to give the child the best possible experience of school and life outwith school.

A number of steps helped this child, her fellow pupils and staff to progress together:

*In full credit to staff they have never had a pupil with Down's syndrome, and they worked through a number of situations and work profiles with Emma over the year. At Emma's final year parents' night meeting her class teacher stated 'it has been a privilege to teach Emma this year, I have learned so much'. Her class have also been wonderful with Emma, without them being on her side, things could have been much worse, and through it all she has networked a group of friends who all look after her wellbeing, and everyone in school knows her. She is also becoming recognised with our local community. It would appear that after a settling in period, the decision to move into mainstream schooling for Emma has been a right one. She is certainly a more mature wee girl since she has started mainstream schooling. This maturity has carried over into home life as well.*

Whilst supports can develop naturally over time, some specific, early actions can be built into the planning for a child starting a new school:

*Once Katrina was attending school full-time the Speech and Language Therapist set up and facilitated a 'Circle of Friends' around her. It has been without question a great success and key to her successful inclusion. The children are natural teachers and although Katrina has benefited greatly from their support, they too have learnt many other new skills. The Circle has played a major role in educating the wider school, where the ripple effect of how others now see Katrina is quite something to behold. Children no longer side step past us, remark or stare at her uncomfortably. Quite the opposite Katrina is now warmly greeted wherever she goes.*

Tackling stigma of any sort needs to begin in the earliest years and schools have a major role to play. A better understanding of disability can only have a positive effect on children generally, and is more likely to arise from direct contact and involvement with children who are initially seen to be 'different'. In the longer term, it may also influence attitudes to volunteering and to improve the perception of careers in the care sector.

This example clearly shows the willingness of peers to look out for their classmate:

*The children have been very supportive and Sandy has made great progress socially because he is following the role models of the other children. The P7 children have set up a 'Buddy System' and take turns helping out at break times and lunch times. One of the problem areas that we have come across is getting Sandy to come into school when the bell rings, so the older children are encouraging him to do this. Sandy's classmates have just accepted him as another member of their class.*

### **Supports for teaching staff**

It is recognised that classes with children with varying needs do pose challenges for education authorities and for staff providing support.

When planning to include children with additional need, teachers need to have enough time to get to know the child before transition. They need to arrange cover, specialist training for some children's communication needs, and strong planning and communication with the receiving teacher, the previous school (if any), professionals and family.

The following describes the approach in one school:

When we first heard that we were to have a child with Down's syndrome in our school, the teachers who were going to be working with him were quite worried. Their main concerns were:

- How would they cope with a Down's syndrome child?
- Would they be able to meet his needs educationally, physically and emotionally?
- How would the other children react?
- Would the education of the other children suffer because he took up so much of their time?

The inclusion of John was very gradual. In the summer term, his mum came to the school and spoke to the P2 class about him. She explained that he had Down's syndrome and that he needed extra help with his learning, but that he wanted to come to this school because he had a sister there. Then John visited the class with his mum and his teacher from the special school.

During this term, there was also training put in place for the P3 teacher who would work with John in the new session. The P3 teacher visited the special school and observed him working with his teacher and with his Special Assistant. She also had some training in Makaton and visited a mainstream school that had a child with Down's syndrome in a class. The teacher was still very apprehensive about her ability to cope and several of our staff were very sceptical about how well this would work.

John has now been part of our school since August and I can only say that it has been a marvellous success story. He has fitted in really well.

## Promoting good health

Young people with learning disabilities and with autism spectrum disorder are at much greater risk than their peers of a range of emotional and behavioural disorders including formally diagnosed psychiatric disorders. A study carried out across England, Scotland and Wales identified 39% of children aged 5-15 years with learning disabilities also with psychiatric disorders, compared to 8% without learning disabilities<sup>36</sup>. Policies relating to children more generally provide opportunities to address this:

- The development of Integrated Community Schools (ICS) in Scotland, described above where there is evidence that for some pupils aspects of health and personal development had improved.
- The national programme for Improving Mental Health and Wellbeing<sup>37</sup> was launched in 2001. The four main aims for action during 2003-06 are:
  - Raising awareness and promoting mental health and wellbeing
  - Eliminating stigma and discrimination
  - Preventing suicide
  - Promoting and supporting recovery.

One of the six priority areas is improving the mental health of pupils. Promoting mental and emotional health, and preventing and reducing mental health problems among pupils and parents requires action at home, in schools and in local neighbourhoods and local settings.

- The *Sexual Health Strategy*<sup>38</sup> is very relevant to children and young people with learning disabilities and with autism spectrum disorder. A *Healthy Respect*<sup>39</sup> initiative takes specific account of the needs of children and young people and there will be a need to ensure that implementation of the sexual health strategy appropriately takes account of the needs of children and young people with learning disabilities.
- A strategy for Physical Activity, *Let's make Scotland More Active*,<sup>40</sup> outlines the strategy for encouraging people of all ages to be more physically active and sets national targets for physical activity in Scotland. Active primary school coordinators and schools sports coordinators, supported by SportScotland, are cooperating to develop physical activity in the context of a whole school approach.

NHS Boards and local authorities are also responsible for developing health improvement plans as part of the work of community planning partnerships.

In general children with learning disabilities and with autism spectrum disorder will receive support from the school health service. Increasingly, there is an expectation that the range of health services should be available for children who need it in mainstream schools. The Audit Scotland report *Moving to Mainstream*<sup>41</sup> makes a number of recommendations relevant to health and local authority services. In particular it states that NHS Boards should ensure that health services can effectively support the inclusion of children and young people within mainstream schools.

It is important that those who have lead responsibility at local level for the above initiatives are aware of the relevance they have to the diverse needs of the population. All these areas of work could and should go some way to meeting the needs of children and young people with learning disabilities and autism spectrum disorder.

## Friendship, play and leisure

During our school years, we develop friendships and become more independent of our families. We take risks and learn about responsibilities. For children with disabilities, it is more likely that decisions about friends and activities will be made by others.

Most people spend time away from their parents and families. They go to school, they visit relatives and friends, and spend time with other people, doing different things. Children have tea or stay overnight at a friend's home, adults may see friends, partners or colleagues outside their own home, go to leisure facilities or clubs, or do evening classes.

*The same as you? 2000 p. 78*

Inclusion needs to be considered outwith the classroom too. There are many policies around that relate to the inclusion of all children within existing local services. Most important are children's human rights:

- the right to access play
- the right to access childcare and childcare services
- the right to access the same opportunities across all services.

We often think about the challenges for services in dealing with the inclusion agenda. We know from Section 1 that most children are looking for a life the same as other children. This is well illustrated in this parent's account of the changes in his son and in the children around him:

*For the rest of the first year there were lots of ups and down and Douglas gradually began to settle in to his new surroundings. I had regular informal meetings with the learning support teacher to keep me in the loop of what was going on. During the year he didn't make huge progress academically or develop loads of new skills but he did change. He matured and developed many of the traits of other Primary 4 boys. Douglas used to come home from the specialist unit looking like he had been wrapped in cling-film all day, everything would still be perfectly tucked in. When he comes out of school now the sweatshirt is squint and the T-shirt is untucked, the hands are in the pockets and he has the rounded shoulders and the slouch that everybody else has. The most profound difference in the first year was however that lots of new people got to know him. Kids have always come over to talk to him when we are out and about, but they have always been kids that I know. Now kids I don't know stop to say*

*hello or to play with him when we are out. He also got a huge pile of Christmas cards that year, actually he got more than the rest of us – he became a member of the school!*

A highlight of the school year for many children is the school trip. But these outings need to be accessible for all and need to comply with the Disability Discrimination Act.

School outings were a problem when they were devised as a reward for all pupils but were not at suitable venues for Jack, and many other pupils. (e.g. Alton Towers 6.00am till midnight).  
*Jack: 'I didn't go on many outings because my guidance teacher said 'Alton Towers is not the place for you'.*

The following extracts from Capability Scotland describe children's frustration with the lack of choice available to them. These barriers to inclusive recreation are sometimes physical and sometimes attitudinal:

- *'I'd just like to go round to a friend's house without my mum.'*
- *'No one ever comes to play with me.'*
- *'My daughter gets really upset when her sister goes to art class and she can't join in. She's capable of taking part, but there is no provision for a child with special needs.'*<sup>42</sup>
- *'I went to a swimming pool, there was no bench, no hoist. I had to get changed on the floor.' 'I'd like to play wheelchair football, but there's nowhere to play.'*<sup>43</sup>

*Scotland Has Never Had It So Good?*<sup>44</sup> a Capability Scotland 1 in 4 poll, found that:

*'Only 18% of respondents attended a youth club or went to Scouts, Cubs, Guides, Brownies. Only 6% attended a junior theatre group. And while the figure of 41% involved in a sports group or activity at a leisure centre might seem high, it is way below the participation rate for non-disabled children. A recent Sportscotland survey found that 80% of 8-18 year olds in Scotland participate in a sporting activity outwith school PE lessons at least once a week.'*<sup>45</sup>

The barriers children with learning disabilities and autism spectrum disorder face with play facilities and out-of-school care include:

- Lack of awareness/understanding of the needs of disabled children (by both adults and children)
- Fear of the unknown/of disability
- Fear of change
- Fear of making a mistake
- Lack of resources (staff time and money) for staff to attend appropriate courses
- Lack of understanding in staff of their responsibilities towards ALL children (If a disabled child attends, it is not clubs responsibility to include, look after, be responsible for child)
- Parents of mainstream children unwilling to 'subsidise' disabled children by paying more to allow club to increase staffing numbers to enable them to better include disabled children

Attitudes need to be changed so that disabled children are accepted as children first (seeing the label and not the child). Inclusive play provision depends on a general acceptance and understanding of the social model of disability.

Inclusive provision is provision that is open and accessible to all, and takes positive action in removing disabling barriers, so that disabled and non-disabled people can participate.

The following transcript of a video describes the work of Achievement Bute in providing children with a range of play and leisure activities:

During school term time Achievement Bute has developed a number of completely inclusive activity clubs, which run in the evenings and at weekends. If you live on Bute its great if football or rugby is your thing, but no sporting activity existed that disabled children could participate along with their non-disabled peers. We set up our 'Right Fit' clubs to meet that need.

We have around 60 children participating each week. The younger children start with 'Brain Gym' where they take part in games and activities to improve their balance and co-ordination. The older children can decide what activities they want to themselves – normally team games such as hockey, lacrosse and rounders, which are adapted, so that every child can participate in. Until recently we ran an activities club for younger children in

which drama, music and visual arts featured predominately, however as the needs and interests of the children have evolved so our clubs have expanded and changed. We now run two stand-alone drama clubs and drama also plays an important role in our after school major access clubs.

Having run a number of one off summer film making projects with children over the last 3 years the kids decided they wanted something more permanent so our 'Screenbites' clubs were built. These are held after school in our local secondary school. We work in partnership with the schools and community education to provide these clubs which are extremely popular and a great opportunity to learn a whole range of transferable skills such as script writing, self-expression and new technology.

Achievement Bute is a parent led voluntary organisation, which was set up in 1998, we support families of children with disabilities and provide a range of activities in which all children can participate regardless of their disability.

Living on a small island, opportunities for children are extremely limited. We feel that we offer a wide range of activities that any child would enjoy. As you can see we have had a very busy and productive year and hope that the summer will bring more of the same.

As well as providing clubs open to all children we also support individual children who may not want to take part in group activities. Our family support co-ordinator works closely with parents and children to determine what is needed and wanted by the individual children.

The co-ordinator says: 'Families we work with in Bute are like families everywhere, they all have different needs, which change all the time. We believe that the best way to support families is to first of all ask them what they need and want. We can provide sessional staff to support individual children if that's what is needed. Some children need extra support to attend local clubs such as guides, brownies or the chess club. I also work closely with other agencies such as physiotherapists, occupational therapists, educational psychologists and social services'.

During the Easter, summer and October school holidays our holiday play programme is designed to provide a range of activities for children on the island. It also gives parents whose children are particularly demanding a break during the long period when children are not at school.

### **First Light Funded Animation Project**

'Skunks, Punks and Battling Bagpipes' is a short animated film made by 22 children as part of our Easter holiday programme. The children based their fantastically bizarre story on a local legend. With very limited adult help they built the set, animated the characters, wrote the scripts and threw in a few sound effects and jokes for good measure. Their film won best comedy in the First Light children's film-making awards in London.

### **Mongolian Mystery**

We are very grateful to the Mount Stewart Trust, which allows us to run our summer outdoor adventure week in the grounds of Mount Stewart. In July this beautiful 300 acre estate was the perfect setting for our Mongolian Mystery, in which over 70 children participated in a week of treasure hunts, woodland games, arts and crafts, drama and stories.

Weaving together the stories and songs and visual arts the children created a magical setting for the week's event – a fantastically decorated story telling pavilion. On the last day the children invited their families to join them for a barbecue and to hear their version of a Mongolian folk tale.

As well as attending special events and structured activities like these, lots of children can use the freedom of their school holidays to go out and play with their friends without constant adult supervision. As some disabled children never experience this kind of informal, spur of the moment play we decided as well as running our structured activities we'd also provide play workers to support individual children in informal settings, with small groups of friends or brother or sisters or on their own. We called these 'Freedom Weeks' and they worked well, giving parents a break and giving disabled children freedom to choose what they wanted to do each day. One child learned to ride a bike, several went to the beach with their friends, and some visited the local farm and some just simply played in the park.

## Person-centred supports during the school years – suggestions for good practice

### Information, training and awareness

Information, training and awareness needs are identified and acted upon

#### Good practice

- In service training is available to all staff
- Continuous professional development training in inclusion is provided for head teachers, class teachers, support staff and other professionals
- Community Planners and relevant staff aim to raise awareness in relation to accessible play and leisure
- All schools (mainstream and special, teachers, parents and children) look at ways of thinking about inclusion and challenging labels and identifying diversity within the community
- Competitions (like the SCLD poster competition) are used to challenge stigma
- Schools share experiences of teaching methods that are successful, such as visual teaching and strength-based work.

### Planning

Planning is done jointly with all relevant parties, including the child and family members

#### Good practice

- Sufficient time is allocated for planning
- Education authorities, head teachers and professionals encourage and support parents' choice to go into mainstream before the child starts nursery, primary or secondary schools
- Schools and families work together to make best use of each others expertise
- The expertise of the special school is transferred to the admitting school
- Visits to the new school are arranged before moving, as early as six months before the child starts
- Meetings with the new school are held before the move to discuss the child's support requirements
- The child is allowed to meet pupils from the new school in advance and make friends.
- Discussions are held with planned classmates to think about the child as an individual with unusual differences
- Funding of staffed play and leisure provision is regularly reviewed to enable it to be adequately staffed

- Community planners provide **AWE**some mainstream recreation and leisure provision (**A**ccessible, **W**elcoming, **E**ngaging) to enable and encourage the inclusion of disabled children
- A range of provision is developed to allow choice (separate provision is acceptable, segregated provision is not)
- Play provision offers children stimulating and challenging environments to enable them to explore and develop their skills, whilst managing the level of risk.

### Supports

Support for children, family members and staff who provide services is put in place and regularly reviewed.

### Good practice

- Young people with learning disabilities and autism spectrum disorder are treated as individuals: they have access to a learning support base that other youngsters use when extra help is needed
- Schools acknowledge teachers' fears. Flexible, appropriate supports are in place to assist teachers to be comfortable with their teaching
- Review meetings are held to make sure the support is in place by the date the child starts school. Support should be flexible enough to grow with the child
- The child or young person knows about the systems in the new school (e.g. if the corridors have a one-way rule)
- Children can access appropriate peer support. Other pupils provide support at breaks, including a Buddy system or 'Circles of Friends' to help develop friendships
- Mainstream schools are physically accessible to all children
- Schools arrange for mainstream and special schools to take part in joint activities so that children get more of a chance to get to know each other
- Support networks and contacts are available for when things get difficult or go wrong.



### CHAPTER 3

## PREPARING FOR ADULTHOOD

The aspirations of young people with learning disabilities and with autism spectrum disorder are similar to every young person's when they leave school. They want to have friends and relationships, to work or study, perhaps to travel, and eventually to have a home of their own where they may choose to live with friends or a partner, and to start a family. Like all young people, they want a good social life. However, until now, this has not been the reality for adults with learning disabilities and autism spectrum disorder.

There are many influences on the choices we make about our future while we are at school. For young people with learning disabilities and with autism spectrum disorder, these choices are often limited by the low aspirations of some, or all, influential parties.

Whilst a child's adult life is shaped from the earliest years, the most crucial period in determining the future is during the transition from school to adult life. The issues discussed in earlier chapters are just as important – and in some cases more important – during the transition period: attitudes, inter-agency working and communication, and natural supports. While there is an increased focus on the need to support people through transition there are still too many examples where this does not happen well. The Additional Support for Learning Act came into force in November 2005 and creates a duty on local authorities, health and social services to work together to develop integrated support for children and young people with additional support needs. However, the need for inter-agency working at the time of transition was clearly set out in *The same as you?*

Future needs assessment and putting it in place is particularly important for young people with learning disabilities.

On leaving school young adults and their families may no longer have access to the same short break services, with which they are familiar and comfortable. And the educational opportunities to learn and develop which they had at school may not be available. Local authorities are responsible for meeting these needs, and for co-ordinating the contribution of other partners (including further education college boards of management). GPs, paediatric, learning disability and physical disability services should agree arrangements for people moving from child to adult services to make sure people have appropriate continuity in the healthcare they receive.

*The same as you? 2000 p. 82*

The transition to adult life has often been described as the most difficult time for young people and family carers. Despite progress in policy development, many families are still facing considerable difficulties.

These difficulties mostly arise because of a failure of planning mechanisms to deliver a continuum of support. For young people this can result in a crucial period in their lives with no clear direction and no goals. For young people with communication difficulties, there is a real risk that their hopes and dreams will not be heard. Finding out what a young person wants for the future is paramount to getting it right for them. It is all too easy to have the adults around them – parents, teachers, school and local authority professionals – leading the decisions made about their future. Additional problems arise where health needs are also not clearly identified and addressed.

For families, a delay in identifying and agreeing the young person's support when they leave school impacts on the lives and relationships of all family members, and, for some, results in a return to a 24-hour-a-day caring role.

There are also resource issues that are not being addressed early enough between child and adult services, particularly where a young person has a high level of support needs. Some young people will continue to need that high level of support for the rest of their lives. However, as is the case with young people who do not have a disability, those with learning disabilities and with autism spectrum disorder should be supported and encouraged to become as independent as possible. The move from a familiar care setting should be seen as a period of transition during which the young person's confidence and abilities are allowed to grow.

One of the key transitional planning mechanisms until now has been the Future Needs Assessments (FNA). These meetings were initially held when a young person was 14-15 years old but were only for those with Record of Needs. The Additional Support for Learning Act introduces new transitional arrangements to ensure an ongoing process of planning, preparation and the effective exchange of information to support children and young people with additional support needs make a smooth and successful move to post-school life – whether that is to education, training or work.

As part of this planning and preparation, education authorities must seek and take account of the child's or young person's views. will be required to liaise with other agencies to ensure a continuum of support for young people with

additional support needs. Preparation for adulthood should involve explicit recognition of the strengths, abilities, wishes and needs of the child or young person.

Education authorities will also be required to liaise with other agencies to ensure a continuum of support for young people with additional support needs. The process of seeking and taking account of information and advice from appropriate agencies should start when it is most appropriate for the individual but it must be completed no later than 12 months before the child or young person is expected to cease receiving school education.

The purpose of obtaining such information is to enable the education authority to consider the adequacy and appropriateness of additional support provided by the education authority and other services in the period up to the child or young person leaving school. This is to support the process of ensuring a good match between their needs and options for subsequent support.

## Barriers to effective transition

### Communication

FNAs, which are no longer statutory were often large meetings held in a very formal style. Many children and young people found these meetings frightening and difficult to participate in. The new post-school planning arrangements under the Additional Support for Learning Act should help to ensure that the people likely to support a young person on leaving school are better targeted. There is no longer a requirement to have a formal meeting and a report. Instead, transition planning should be embedded within the education authority's policies and procedures for additional support needs. The planning arrangements and support required should be reflected in whatever educational plan(s) the child or young person has. This could be through personal learning planning, Individualised Educational Programmes and/or co-ordinated support plans.

In order for children and young people to take an active role in their transition planning they need to learn about decision-making, about their rights and about how to express their views in a gradual structured way throughout schooling.

Person-centred planning is a good way of ensuring that the individual really has control over the planning process. Most children and young people rely on adults (usually their parents or teachers) for information about their additional support for learning. This means that the extent to which children and young people are involved is usually dictated by the approach of an individual school, teacher or parent.

However, the code of practice, which accompanies the Additional Support for Learning Act, contains a chapter on how children, young people and their parents can be involved successfully in education and learning and describes the Act's provisions on supporters and advocates. Education authorities and appropriate agencies must have due regard to the code when carrying out their functions under the Act.

The code makes it clear that all children and young people should have the opportunity to make their views known, to express their opinions and to have them taken seriously, particularly in relation to decisions which affect them. For some children and young people with additional support needs, expressing their views will be fairly straightforward. For others, a range of approaches may have to be taken to determine their views, such as the use of alternative or augmentative communication systems or getting the views of other family members who know the child or young person well or the use of an advocate.

The Additional Support for Learning Act provides young people and parents with the right to have a supporter or advocate present at any discussions or meetings with an education authority with regard to the authority's functions under the Act. Education authorities should make parents and young people aware of this right and how to access these services.

The amount of information given about post-school options and the way it is presented to the young person and their family also has a big impact on their ability to make informed and appropriate choices.

The example below shows how good communication can be achieved.

All young people face important and sometimes difficult choices when getting ready to leave school. It is so important that young people understand the options available to them and are able to express their views and make choices.

One school where I have done consultation work in the past had a particularly impressive commitment to making sure this happened. The school worked with pupils with severe and complex needs many of whom did not use speech. In the Post 16 unit there was an enormous emphasis on developing effective methods of communication and then using these methods to make sure pupils were actively involved in decisions about their future. Pupils used a whole variety of ways to get their views across. Some used communication folders with graphics / photographs and eye pointed, others used voice output communication aids (a sort of electronic talker) others head movements to indicate yes and no. For the more formal parts of the transition process (for example Future Needs Assessment Meetings or Annual Reviews) pupils spent 1 to 1 time with members of staff preparing, exploring different possibilities and deciding which they preferred. A lot of time and effort was taken to make sure pupils understood what was going on in what is really a very adult orientated process. Pupils were supported to give their views during the meeting and then had a chance to talk about how it had gone with staff after the meeting. One young person made it clear during preparation work that she did not want to attend any meetings but would prefer to meet people (in this case the educational psychologist) on their own; the school were then able to accommodate this.

In addition the school has set up a transition group where pupils get the chance to find out about and discuss issues that may affect them. For example, what does a social worker do, do I have one?; what about transport? etc., etc. The unit has also been working hard developing communication passports for everybody. Pupils have chosen pictures and photos to describe things they like and don't like, people that are important to them and so on. This lets them tell new people a bit about themselves when they meet.

Information from Children in Scotland showed that children and young people supported the idea of a keyworker – someone who could provide information and support to them who is independent from the school. They favoured the idea of being able to access a keyworker as and when they required this support.

## Planning

Good planning over a realistic timescale, and good communication between the schools, other agencies, parents and child should be the basis of any transition programme. Decisions about funding should be taken early enough to support this process, not put it in danger.

John and his father were worried when they heard nothing from the college over the summer and both he and John were surprised to learn that this was because John had not applied to go to college. All of the professionals involved were unclear as to who should have made John and his parents aware of the application procedure to get him into college, but everyone has learned from this. The local college have now employed a Social Inclusion Officer whose job it is to go to all of the mainstream and special schools in the area and identify students who would benefit from the courses offered and work out the supports that would need to be in place for these pupils to attend mainstream college.

Funding issues have sometimes jeopardised good transition practice. Although planning was started well in advance by schools and other agencies, decisions about funding were not made until the last minute (sometimes days before the young person left school) resulting in a failure of the whole process.

## Offering real choices

Supporting people with learning disabilities and with autism spectrum disorder to have meaningful choices about their lives is embedded in the principles of *The same as you?* The path most of us follow beyond school leads to employment or further education.

## Employment

It is often assumed that children with learning disabilities will not be able to take up employment when they leave school, and few have the same opportunities for work experience as their non-disabled peers. Children who have been educated in special schools may need their confidence building to believe that they are capable of getting a job. Self advocacy support can be vital here.

*Working for a change?*<sup>46</sup> looks closely at the reasons why many people with learning disabilities who want to work do not have that opportunity. Whilst there are many agencies that can bring about a shift in practice, it is important that schools include children with learning disabilities and with autism spectrum disorder in preparing for employment. This can be done by ensuring options for school leavers are as varied as people's needs and aspirations. These should include:

- Paid work
- 'Gap year' opportunities to pair up with another young person to travel, live and work internationally
- Leadership opportunities like the Princes Trust or Fairbridge
- Mainstream training for work opportunities
- Volunteering opportunities
- An integrated college course.

### **Andy's Story – Work Experience at Special School:**

*Andy's school was offering cleaning the staff room and dealing with tea money as work experience. I believed this wasn't appropriate for any child and I knew there had to be better experience available for him. I voiced my concerns to Andy's very supportive educational psychologist.*

*I had heard of an independent group in the area who run youth hostel style accommodation in a social firm format. I felt they would be supportive of Andy trying some work with them. The high school was happy to give the auxiliary hours to support this work experience.*

*The placement staff were really keen for Andy to go one day a week and learn some cleaning, gardening, laundry tasks, and perhaps deliver laundry to the local villagers. Once the supports were in place he started in October 2003. Andy loves a Friday and asks to go to his placement several times a week. He even wanted to wear his polo shirt with logo during the recent Easter holiday – that's how much he appreciates his time at work.*

*A teacher at school has taken photos of all the activities Andy does at work in sequenced photos, including the bus journey and going to buy lunch at the bakers and grocers. His little book of photos gives him good cues to the work and activities he will be required to do at work. He has a photo of himself to put in the slot at work to sign in and out and 'Boardmaker' symbols are on the door to show him and anyone else with learning disabilities where things are.*

*The staff expect him to be part of their workforce and allocate him tasks appropriate to him but need done that day. His auxiliary supports him hand over hand to complete the tasks and sees to his personal care needs. He is practicing many skills that are transferable, including hoovering, dusting, washing woodwork, making beds, stripping beds, folding laundry, putting laundry in a washing machine, delivering laundry, sweeping up leaves, watering flowers, and washing dishes – the list goes on.*

*One of the wonderful things about this work has been a connection between Andy and a man who helps out. They have really clicked and this has helped both of them to get a lot out of working. A looks forward to working alongside someone who now goes on a Friday to see him. Very few people are in Andy's life who aren't paid to be there and this makes a big difference to him. It also gives us the confidence to know this can happen again for our son, something we strive for in all the things we do in guiding him in his life.*

*I feel this experience is giving Andy a foundation on which to work from when he leaves school at Christmas.*

*Having the information to guide me about supported working options and a friend who put me in touch with a welcoming workplace was the key I feel to this success story. What I know from my daughter's experience at school is that a taster at work is crucial to feeling part of the transition to adulthood, as it's the first practical experience that focuses on life after school and something individual to you. I knew that Andy was going to miss that opportunity cleaning the staff room at the special school.*

*The main thing that changed Andy's experience was a willingness to try something different with the available support hours. Pushed by Andy's psychologist initially, our Education Department now have someone who hasn't gone down the established route to compare outcomes with.*

## Further education

Young people feel there should be greater flexibility in terms of the age at which pupils leave school and that those who feel they need an extra year or two at school should be able to get this.

### **Struan's story:**

*There was inflexibility in standard grades in not being allowed to spread them over 2 years. It made the year in question very hard work, and also meant that there was not much to do in the following year as highers would be beyond him. We do not think that enough effort was made by the school to organise real school work in 6th year. Transition to college which is ongoing, has been a negative experience, though some steps are being taken by the school to retrieve the situation. College has not been prepared for pupils from mainstream arriving at 16.*

As with work, young people with learning disabilities have a different experience of further education. Choices are often limited to life skills courses or special college. Whilst life skills courses are clearly of benefit to some people at particular stages of their lives, many find themselves in a cycle of repeated courses with little motivation or sense of achievement. Based on the principles of *The same as you?* people with learning disabilities should be able to access mainstream higher education. They should be able to work towards real qualifications that will help them into work. Whatever, the course, young people should be able to put their learning into practice and gain from that learning experience.

### **Martin's story:**

*Martin was 21 in September 2004, and is in the middle of a four year course (NVQ Lifeskills) – these involve Work Skills, Social Skills and Living Skills. He attends college two days of the week.*

*The remaining three days are spent at the Adult Training Centre practising the college lessons and also attending work training lessons organised by the Adult Training Centre – he also does a lot of physical activities to help with his physical and motor skills. He is supported by four support workers paid for by the Independent Living Fund. The only main issues at the moment in his life are transport to college (college won't pay as he is not a full time student as described earlier) and supported employment (very few employers want profoundly disabled employees!!) but his family are working on this at the moment!*

Getting the right level of support at college is crucial to success, and this needs advance planning and preparation. Young people welcome opportunities to visit the place they are moving to and to meet staff face to face.

Young people consulted by Children in Scotland said colleges and universities need more training in practical aspects of support as well as attitudes. They felt staff should be honest about the supports they could offer. A more individualised approach would help further education establishments get to know all their students really well, ironing out some of these problems. Once more, forward planning and a commitment to acting on any plan is a key to success.

The transition to college is fraught with funding issues for support, debates on who will pay for what, and so on. Funding for a young adult with additional support needs comes from a plethora of sources making it a nightmare for parents to understand let alone negotiate. They are at the funders' mercy.

*Partnership Matters*<sup>47</sup> was published by the Scottish Executive in 2005 to ensure that appropriate partnerships are in place between further education colleges, local authorities and NHS Boards to support people with additional support needs studying in further education. This outlines the roles and responsibilities of each agency, and sets out examples of good practice and the outcomes that this delivers.

### **Supporting independence**

The development of advocacy, direct payments and local area co-ordination will all have a major influence on a young person's transition to adult life. These are discussed more fully in Section 3.

Leaving school should be a time when young people have a vast array of options. What is needed for young people with learning disabilities and with autism spectrum disorder is a forward looking life plan that looks at their choices for their future, but is flexible enough to change as the person changes.

Crucially, individualised supports need to be in place before the young person leaves school, so a bridge is built that is not in stone, but gets them easily to where they are going.

There are a number of resources that assist with the transition from school. These include:

- Mencap's 'Trans-active' is a project in which teenagers with and without severe learning disabilities work together. They use multimedia to explore and communicate choices they will have when they leave school. The project is about using and giving support, making plans, making friends and having fun.  
(Link: <http://www.trans-active.org.uk/>)
- ENABLE Scotland's Transition CD-Rom will be ready in the Autumn of 2006. It is an interactive CD-rom aimed at young people with learning disabilities. It will help them make a more informed choice about life after school. Professionals and parents will be encouraged to use this CD-Rom as a tool to 'listen to the voice of the young person'.
- *MOVING ON to adult life* – a resource pack written by families in Fife to help young people with additional support needs and their families to plan for the future.  
(Link: <http://www.otbds.org/articles/MOVINGONLEAFLETorder.pdf>).

## Person-centred supports during transition – suggestions for good practice

### Planning

Planning is done jointly with all relevant parties, including the young person and family members.

### Good practice

- Person-centred planning begins early enough to allow options to be explored – at least 2 years before leaving school.
- Support packages and funding are agreed well before (at least 6 months) the young person leaves school.
- Children and young people receive accessible information and are involved in decision-making.
- Young people visit new schools/colleges and have opportunities to meet new staff and pupils before moving.
- Child and adult services are jointly involved in future planning with young people and their families from the outset. Financial agreements are finalised in advance of the child leaving school.
- Personal life plans take account of the young person's potential to become more independent and to change.
- Training on additional support needs is provided for college and university staff.
- Potential employers receive training and support to encourage them to employ young people with learning disabilities and with autism spectrum disorder.
- Children and young people with learning disabilities are supported to be included in groups involved in planning services.

## Communication

Everyone involved in planning transitions communicates clearly with each other in accessible ways.

### Good practice

- Children and young people are taught about decision-making, their rights and how to express their views in a gradual and incremental way throughout their education.
- There is a flexible approach to meetings – large meetings may not be the best way for children and young people to give their views.
- Children and young people understand the options open to them. They know who people involved in the process are and what they do. Jargon is not used.
- Children and young people and their families receive accessible information about a range of independent advocacy services, including self-advocacy.
- Young people and family carers are kept up to date with plans at all times.

## Supports

Support for children, family members and staff who provide services is put in place and regularly reviewed.

### Good practice

- Children's and adult services work together to ensure families know what supports will be in place when the young person leaves school.
- Schools work with local colleges to identify appropriate courses for young people and agree the necessary support to enable them to attend.
- Support throughout the week is flexible, and not restricted to days at college.
- Young people have access to local area co-ordinators, who help them to identify and take forward their personal plans.
- Young people have access to advocacy services to support them to speak up for themselves and to make their own informed decisions.



### SECTION 3

## WORKING TOGETHER FOR CHILDREN AND FAMILIES

This report emphasises the need for agencies to work together to ensure current implementation of *The same as you?* addresses the need for children and young people with learning disabilities, and with autism spectrum disorder, to lead ordinary lives. It recommended a number of specific developments that will assist this shift to greater choice, independence, and social inclusion.

### **What will progress look like?**

*The same as you?* sets out a few simple measures of progress towards new and better ways of working, and a better quality of life:

- Local area co-ordinators will be the focal point for securing services and support.
- Independent advocacy and direct payments will give people more control of their lives and the services they receive.
- People with learning disabilities and autism spectrum disorder will be much more part of the community in which they live and work and enjoy education leisure and social activities.
- People with learning disabilities and people with autism spectrum disorder will enjoy better health.
- And bullying and harassment will not be tolerated.

*(The same as you? 2000 p. 119)*

### **Local area co-ordinators**

In Western Australia, local area co-ordination is driven by the needs of individuals, and it supports people to live in their own communities. Based around this model, *The same as you?* recommended the appointment of local area co-ordinators (LACs) in Scotland, providing a specialist worker to help individuals and families through the maze of systems they come into contact with when they are in need of support.

Whilst the roll out of local area co-ordination across Scotland is still at an early stage, evidence from LACs and from family carers suggests that this new role is key to providing the kind of information, advice and supports that families want.

*'Information-wise parents don't need a lot. We just need good quality information and some people that understand.'*

Most LACs are funded through social work services for adults, some from the change funds allocated through local authority community care resources to support implementation of *The same as you?* In one area, Changing Children's Services funds have been used to appoint a LAC.

LACs go out to a range of services: including informal and formal groups, schools, employers, leisure and recreation. An example of LAC activity in one area has involved meetings with childminders, the Forestry Commission, schools, and professionals in a number of agencies to tell them about the role. The LAC has also helped develop youth work training to support young people in social activities, adapted an environmental studies booklet for an inclusive programme for adults, and offered input to training needs for childminders.

LACs can assist with:

- Awareness raising
- Influencing attitudes
- Play facilities/out-of-school care
- Transitions – between nursery and school, between primary and secondary school
- Leaving school
- Making links with FE colleges
- Finding out about rights

At this stage there has been little monitoring of the role and remit of the LAC, and there is lack of consistency between authorities. However, evaluation of local area co-ordination is presently underway and the results of this work will be available later this year, informing future development of this service.

Some LACs provide a service for a limited age group, such as older people or teenagers. However, anecdotal evidence indicates that the benefits of this type of role have particularly been welcomed by families with young children who are coming in contact with services for the first time. The role was envisaged as a means of providing information and support to families who were not receiving a service. For some, information and direction to other agencies is all that is needed. For others, concerns about engagement with services has prevented them seeking support.

*'Half of the families have no social work involvement. They don't want people asking questions. The detail of questions is a huge barrier. If you use respite your child becomes looked after and accommodated. Parents don't want this, so families just get on with it.'*

Keyworkers are recommended in a number of policy developments, as discussed in Chapter 1.

The benefits of this kind of support may also lessen the need for more expensive services, or for crisis interventions. It would therefore seem appropriate that other agencies give more consideration to funding posts along the LAC or keyworker model. A review of the Changing Children's Services Fund<sup>48</sup> considered that these funds enabled joint working to be developed more quickly, particularly through the appointment of integration managers to co-ordinate joint service arrangements, co-location and service mapping. By focusing on service integration and providing ring-fenced funds specifically for this purpose, areas were prompted to devote time and resources to providing local delivery and a co-ordinated cross-agency service.

To achieve the best outcomes, particularly for the most disadvantaged children, it is essential that all agencies work together effectively. There is clearly a demand for a professional who is based in the local community and who can develop strong networks and community links. We now have good evidence from Sure Start Scotland that bringing the skills and expertise of a range of disciplines together in an integrated service can bring real benefits for families. These services can provide access to a wider range of more effective supports, reduce stigma and promote reorientation of support towards prevention, health promotion and early intervention.

## **Advocacy**

Along with this report, SAYIG is publishing a report on advocacy. There is confusion about the role of advocacy, and the different types available. The report describes these and how advocacy sits within a context of person-centred services and supports. It describes the importance of advocacy to:

- help people have their say
- add weight to a person's ideas, wishes and opinions
- challenge attitudes and perceptions
- socially include people
- protect people's rights.

The report is just as relevant to children and families as it is to adults with learning disabilities and autism spectrum disorder. For children, it is important that their voice is heard too, and not just the voice of professionals and other family members.

ENABLE Scotland have been developing self-advocacy for young people with learning disabilities from across Scotland for the past 5 years. They currently have a national group of young people with learning disabilities aged between 13 and 25 from across Scotland who campaign on matters that affect their lives. This group of young people have contributed their views on a wide range of policy matters including the records of needs, free school meals campaign and engaging children and young people in community planning. Examples of their work can be found in the young peoples section of the organisations website [www.enable.org.uk](http://www.enable.org.uk)

### **Direct payments – self-directed care**

*‘Direct payments opened the door to a new life for my son, my husband and myself. They enabled us to be creative, have flexibility and opened the flood gates for choice. Direct payments normalised our lives.’*

Direct payments – or self-directed care – offer:

- Flexibility
- Choice
- Control
- More opportunities
- New people and relationships
- Independence
- Creative solutions
- Being a part of your community

Instead of a social work department organising the services for a child or family, those who are entitled receive money for the service they are assessed as needing. They can then use the money to buy the kind of help they feel the family needs most. It also allows people to choose the staff that will work alongside the family.

According the law, every local authority in Scotland has a duty to offer direct payments. This duty includes families who have a disabled child, parents with disabilities, young people aged 16-17 with disabilities and adults (including older people) with learning disabilities.

Take up of direct payments amongst people with learning disabilities is beginning to grow. Statistics produced in 2005<sup>49</sup> indicated that 315 people with learning disabilities of any age are accessing direct payments. Work is ongoing to improve this, like the booklet *An easy guide to direct payments in Scotland*<sup>50</sup> published by SCLD and Direct Payments Scotland with funding from the Scottish Executive.

Direct payments can be accessed through a social worker. When a child or family is being assessed for social work services, the social worker should make the parents or family aware that they can get direct payments as alternative to social work services.

### **Advantages of direct payments**

Direct payments aren't right for everyone as some people might find the work that would go into managing difficult and time-consuming. However the story that started this section highlights that for those that do decide on the route of direct payment there can be many advantages. These include more choice and control over the service offered, who delivers it and how it is delivered. In turn this can mean a great deal of flexibility for families since the support can be tailor-made to suit them.

As the supports families get through direct payments don't have to be tied to services, it could mean that the child or young person will have increased access their local community, meet new people and become independent of their family

Direct payments can also be used to overcome some of the concerns families have about their child being termed as 'looked after' whilst getting respite. Providing that the parent is in control of the respite or short-break arrangements, direct payments guidance indicates that the child won't be considered 'looked after' under the terms of the Children (Scotland) Act 1995<sup>51</sup>.

Direct payments can also be a useful tool in transition planning for young people. Young people aged 16-17 can apply for direct payments in their own right and could be used creatively to ease the passage to adult services.

Above all direct payments have the potential to offer real family-centred support, ensuring families get the support they feel they most need, when they most need it.

## **Barriers to direct payments**

As the figures suggest not that many people in Scotland are using direct payments yet, although numbers are increasing. One of the issues affecting this can be local authorities not seeing direct payments as a real alternative to offer families. Social work department money is often tied up in existing services which can make it difficult to offer support in a different way.

Also, not everyone feels direct payments are right for them because of the need to consider the responsibilities of being an employer, managing the money and organising the support. However, families don't need to be on their own with these tasks, there are support organisations across Scotland who can help ease some of the burden of this work.

Other things that might concern families is the issue of disclosure checks. This procedure is carried out for all potential employees who will be working with vulnerable people and children. At the moment, local authorities and support organisations have different views about who is the 'employer' and therefore who applies for the check where direct payments are being made. However, there is further work being done in this area and this should make it clearer where responsibilities lie. And people who want to use direct payments can access staff who have already been recruited by local authorities and other agencies.

It is clearly very important that the recruitment process for hiring staff to work with a child or young person is robust. Putting time and effort into the recruitment process can be a much better way of guarding against getting the wrong person.

## **Moving direct payments forward**

Although there are some issues to be ironed out, the potential offered by direct payments to families is great. Families can be the drivers of moving forward direct payments by asking their local authority about direct payments and working together to sort out problems. By encouraging local authorities to use the duty there will be the opportunity to get a real picture of how successful and cost effective direct payments can be. The Scottish Executive will also be working with a specific group of stakeholders to improve information about and access to direct payments for families of children with disabilities.

A local authority in England provides a good example of how creative thinking can lead to increased flexibility and better outcomes for families.

Essex has set up a separate team for financial monitoring of adult services. This has led to more flexibility in the monitoring and processing of direct payments for children's services. The local authority has acknowledged that families' demands for direct payments can vary across the year. It is likely that families will need more support during holiday times and less during the school term. Therefore, each case is dealt with on an individual basis and the local authority will consider six-monthly rather than monthly payments.

## Health

Earlier chapters describe the health inequalities experienced by children and young people with learning disabilities and autism spectrum disorder. NHS Quality Improvement Scotland has developed Learning Disability Quality Indicators<sup>52</sup>. These apply to all people with a learning disability, including children. This is to ensure that the quality assurance process considers services for people with learning disabilities in their entirety, including the transition from children to adult services.

Following a programme of work monitoring progress across Scotland against these indicators, a *National Overview*<sup>53</sup> report was published in February setting out a number of recommendations. It recognised that there are not dedicated services for children with learning disabilities in most NHS Board areas, but found community child health services/services for children with special needs provide services for this group. This generally includes children and young people who have autism spectrum disorder.

The inclusion of children with learning disabilities in this National Overview was considered relevant in the absence of other child health standards or indicators. The work developing on joint inspection for children will in time integrate the Learning Disability Quality Indicators, as relevant to children and young people. It is important that any performance indicators for children's services address the needs of children about whom this report is written.

- Including children with learning disabilities and autism spectrum disorder in the *Action Framework for Children and Young People's Health Services* will ensure that their needs are taken account of with measurable improvements in their health
- Children with complex needs will have good multi-agency care co-ordination
- All children and young people will have access to appropriate and effective child and adolescent mental health services if they require to
- All children with learning disabilities and ASD will benefit from health improvement programmes which will take specific account of their needs
- The Child Safety Action Plan will take account of children and young people with learning disabilities to help reduce the number of accidents and provide safer environments
- Children and young people with learning disabilities and ASD will be supported through transitions and have continuity of health care. Community Health Partnerships with local authorities can help this by ensuring there are integrated care pathways in place.

## Conclusion

The real measure of success of *The same as you?* and all related policy described in this report will be a better quality of life for people with learning disabilities and with autism spectrum disorder.

For children in the future the real measure of success will be a life without disability labels, where mainstream services deliver specialist support for those who need it.

A child's needs will relate to the community in which they live. Communities that are strong and vital will be more nurturing places for children to grow up and learn. Strong communities will have effective community links, accessible services such as health, education and childcare, good transport options, places to buy good quality nutritious food, decent, affordable housing and low crime levels.

Communities in turn will benefit where the families and children who live in them are healthy, resilient, well-adjusted and able to contribute to that community.



**ANNEXES**

## Annex A: Children's Sub Group members

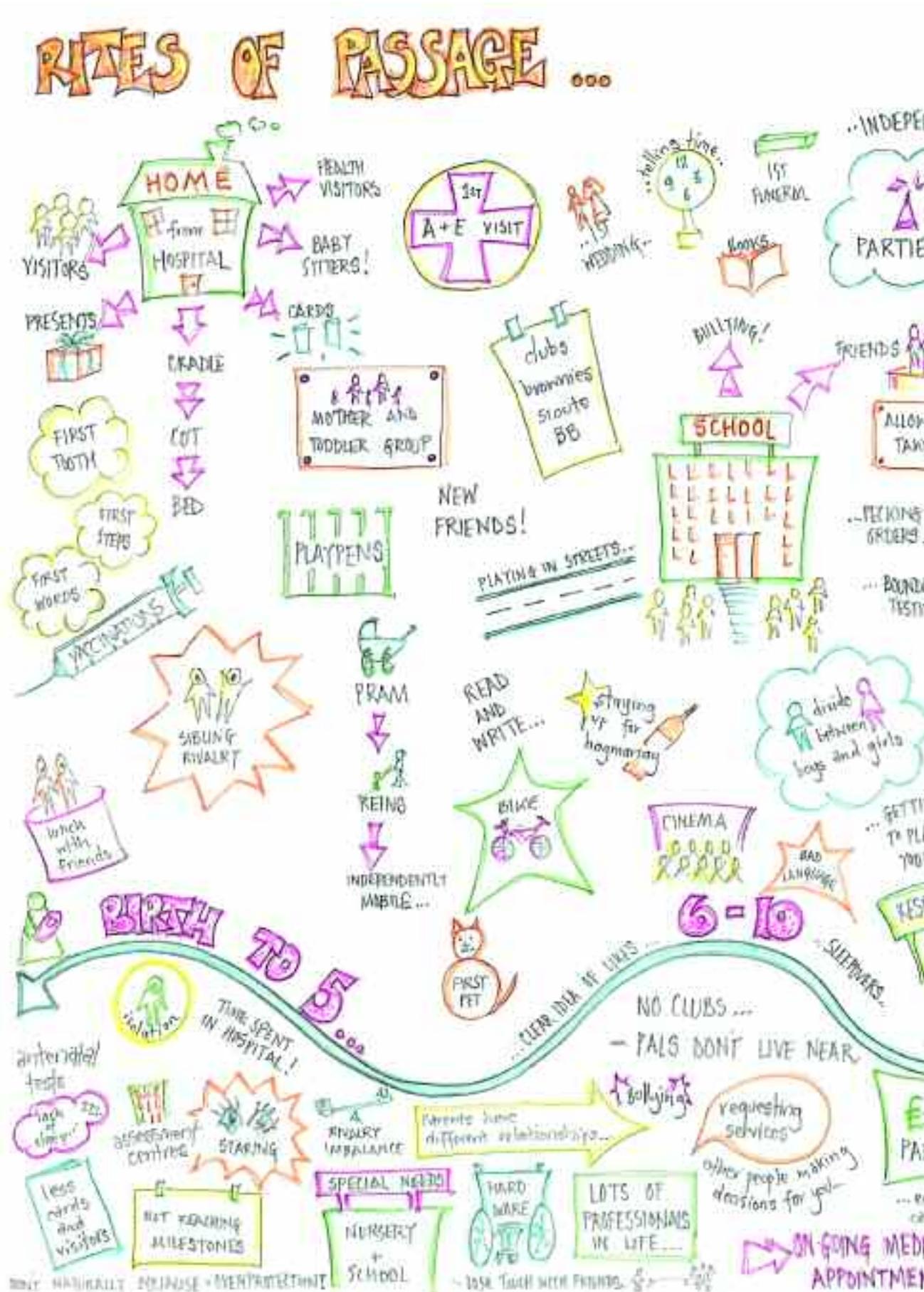
Fiona Allen	Children's Services Change Manager, Aberdeen City Council
Karen Bain	Children's Worker, Down's Syndrome Scotland (co-chair)
Richard Brunner	Policy Advisor, Scottish Human Services Trust
Lisa Curtice	Director, Scottish Consortium for Learning Disability*
Ali Drysdal,	Local Area Co-ordinator, Dumfries & Galloway
Caroline Dunmur	Children in Scotland
Bette Francis	Scottish Executive Health Department
Pat Jackson	Lothian University Hospitals Trust
Fiona McFarlane	Capability Scotland
David Miller	Scottish Executive Education Department
Catherine Montgomery	Children's Officer, ENABLE (co-chair)
Jan Murdoch	Education and Communication Manager, Scottish Consortium for Learning Disability*
Liz Platt	PAMIS
Lesley Stalker	Parent Representative, Down's Syndrome Scotland
Albi Taylor	Parent
Fiona Wallace	Director, People First (Scotland)

Margaret Whoriskey

NHS Quality Improvement Scotland until February  
2005 then Scottish Executive Health Department

\* Jan Murdoch replaced Lisa Curtice as the SCLD member of the Group

Annex B: Rites of passage





## Annex C: Policy and Law

The following list sets out legislation and policy that links to the content of this report.\*

### Legislation

#### Equality issues

Equality for all underpins Executive policies. It allows schools, local authorities and other agencies to address additional support needs which may arise as a result of inequality and discrimination.

Article 14 **The Human Rights Act 1998**<sup>54</sup> incorporates the European Convention on Human Rights into Scots law. It supports the requirement for local authorities and other bodies not to discriminate on grounds such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

The **Disability Discrimination Act 1995**<sup>55</sup>, as amended, requires local authorities and schools not to treat disabled pupils less favourably and to make reasonable adjustments to avoid putting them at a substantial disadvantage.

The **Education (Disability Strategies and Pupils' Educational Records) (Scotland) Act 2002**<sup>56</sup> places a duty on education authorities, managers of grant-aided schools and the owners of independent schools to prepare a strategy to increase, over time, the physical accessibility of the school environment and the accessibility of the curriculum for pupils with disabilities and prospective pupils with disabilities. The strategy must also provide for the improvement of communication with pupils with disabilities, especially in relation to the provision of school information.

s23  
s6 The **Children (Scotland) Act 1995** establishes the responsibilities of services, providers and parents in matters affecting children's care and welfare. Local authorities must provide services designed to minimise the impact of disabilities on children and to allow them to lead lives which are as fulfilling as possible. Children's views must be sought and taken account of in key decisions that affect them.

The **Race Relations (Amendment) Act 2000**<sup>57</sup> places a general duty on public bodies, including education authorities in respect of schools they manage, to eliminate unlawful racial discrimination and to promote equality and good race relations. Education authorities must have a race equality policy and make arrangements for schools to monitor and assess the impact of their policies on pupils, staff and parents from different racial groups, including in relation to attainment.

### **School education**

Under the **Education (Scotland) Act 1980**<sup>58</sup> education authorities must provide adequate and efficient school education for children of school age within their area. The **Standards in Scotland's Schools etc. Act 2000**<sup>59</sup> places education authorities under a duty to secure that the education provided is directed towards the development of the personality, talents and mental and physical abilities of the child or young person to their fullest potential.

s15(1)(b)  
and s40  
2000 Act Education authorities should provide education to school age pupils in a mainstream setting unless certain exceptions apply. Education authorities must make special arrangements for pupils who are unable, or where it would be unreasonable to expect them, to attend school through prolonged ill-health.

s2(2)  
2000 Act Education legislation gives certain rights to parents and young people rather than to children in their own right. However, the 2000 Act recognises that children should have the right to express views on issues that affect them. Chapter 6 of the code describes where children's views should be taken into account under the new Act.

- s2 Age of Legal Capacity Act 1991<sup>60</sup> The new Act also sits alongside legislation which recognises that children with legal capacity are able to make some decisions on their own behalf. For example, a child over 12 may consent to any medical procedure or treatment and instruct a solicitor in relation to civil matters so long as he or she is considered capable of understanding their nature and possible consequences.
- Young people** (young persons in legislation) have similar rights to parents regarding school education. They may also express their views on, and take decisions about, their school education.
- Adults with Incapacity (Scotland) Act 2000<sup>61</sup> The law provides for decisions to be made on behalf of adults who lack legal capacity to do so themselves because of mental disorder or inability to communicate. Adults are defined as being age 16 or over. The decisions concerned may be about the adult's property or financial affairs, or about their personal welfare, including medical treatment. Professionals carrying out functions under the Additional Support for Learning Act should have due regard to the provisions of the Adults with Incapacity Act.
- s30 1980 Act **Parents**, under the 1980 Act, must ensure that their children of school age receive adequate education suitable for the age ability and aptitude of their child, either by sending their child to a school managed by the education authority, or by other means, for example an independent school or home education.
- Children (Scotland) Act 1995 Parents must, where it is in the interests of the child and is practicable, safeguard and promote their child's health, development and welfare. This also applies to anyone over 16 who has care or control of a child under the age of 16. In addition, parents can provide their children who are under 18 years of age, with appropriate direction and guidance. They should maintain personal relations and direct contact with their son or daughter on a regular basis, if they do not live with their child. Parents can also act as their child's legal representative. Where a person takes a major decision in fulfilling a parental responsibility or right under the 1995 Act they must have regard to the views of the child, taking account of the child's age and maturity and whether the child wishes to express a view.

## Other legislation

The **NHS Reform (Scotland) Act 2004**<sup>62</sup> provides the legislative framework for the development of Community Health Partnerships which lays strong emphasis on partnership, integration and design.

The **Protection of Children (Scotland) Act 2003**<sup>63</sup> introduced safeguards to prevent unsuitable people from working with children. The Act covers a range of childcare positions defined in the 2003 Act, not just those involved in directly caring for, training, supervising or being in sole charge of children. It includes those whose normal duties include work in educational establishments or in hospitals which are mainly for children.

Professionals carrying out functions under the **Mental Health (Care and Treatment) (Scotland) Act 2003**<sup>64</sup> should have due regard to the provisions within education legislation, as there may be instances where there is some crossover between them.

The **Antisocial Behaviour etc (Scotland) Act 2004**<sup>65</sup> introduces Parenting Orders which are compulsory measures designed to support people to improve their parenting where they have been identified as needing help with their parenting skills. Antisocial Behaviour Orders are introduced for 12 to 15 year olds and are intended to deal with a small number of persistently antisocial young people for whom available alternatives are not working. The Act gives the Reporter and a children's hearing power to refer a child who has been excluded from school to Scottish Ministers if it appears that the local authority have failed to comply with its duty to provide education to excluded children and young people. These aspects of the Act could lead to a child or young person having additional support needs. Children and young people who become looked after could be particularly vulnerable in any of the above circumstances.

The **Further and Higher Education (Scotland) Act 1992**<sup>66</sup> requires that adequate and efficient provision of further and higher education is made in Scotland. Due regard should be given to the requirements of those over school age who have a learning difficulty or disability which may affect their education. In preparing young people for leaving school, teachers should be aware of legislation covering further and higher education. Under the **Further and Higher Education (Scotland) Act 2005**,<sup>67</sup> the Scottish Further and Higher Education Funding Council must have regard to the support needs of students and prospective students of further education colleges and higher education institutions.

## Policy

The Scottish Executive has a wide range of policies which support the development and wellbeing of Scotland's children and young people. The following paragraphs describe some of these policy areas that have not all been covered fully in the main report.

### Integrated Children's Services

Local authorities, NHS Boards and other appropriate agencies are expected to work together to ensure effective integrated children's services. In doing so, they require to draw together core statutory and other planning requirements into a single statutory plan. These include Children's Services Plans, Statements of Education Improvement Objectives and Records of Achievement, child health elements of Local Health Plans, Joint Health Improvement Plans and Child Health Strategies, and Youth Justice Strategies. **Integrated Children's Services Plans** must include reference to services for vulnerable children and children in need, including arrangements for early intervention and support within universal services and targeted additional support where required. Given the broad concept of additional support needs there is a need to integrate policies to ensure that factors affecting vulnerable children and children in need do not lead to an adverse effect on their learning.

The Scottish Executive report, *For Scotland's Children*, highlighted the importance of an integrated approach to service delivery and the need for better information sharing between agencies. The Scottish Executive is developing a model for an Integrated Assessment Framework which will support agencies to work together. The aim is to facilitate efficient and effective information sharing and assessment and lead to integrated support for children across all agencies. The framework will be based on a common set of core data that can be shared across organisations. The duties on other agencies to assist education authorities meet their duties under the ASL Act will help the development of such an integrated approach to the provision of school education, family support and health services.

The Scottish Executive's approach to delivering **integrated early years services** is aimed at giving young children, up to the age of 6, the best possible start in life. It offers a framework for the effective provision of universal and targeted services for children and their families and provides a vision of integrated early years services based on partnerships at all levels.

Building on existing provision, Scottish Ministers want to see the development of multi-faceted services, bringing together childcare, pre-school education and some healthcare services focused on young children.

The Scottish Executive report *Better Behaviour – Better Learning*<sup>68</sup> provides recommendations for schools and education authorities to develop a policy framework and appropriate practices to promote **positive behaviour** in schools. These policies and practices should enable school staff to ensure that learning and teaching takes place with the minimum of disruption through good classroom and school management, and through a clear understanding of all staff and pupils of expectations for behaviour. *Better Behaviour – Better Learning* recognises the importance of early intervention and of co-ordinating support for pupils with behavioural difficulties.

The Scottish Executive also has a wide range of policies across health, social work and other agencies which supports children and young people who have additional support needs.

## Health

**Community Health Partnerships** are beginning to take shape across Scotland. These partnerships will have a significant influence on the organisation and delivery of person-centred locally integrated services. They will be a focus for integrating primary and specialist health services at a local level, will help advance and deliver the health improvement agenda, and will influence the deployment of resources. They will also have a lead role in the delivery of services for children and young people at a local level.

*Community Health Partnership Statutory Guidance*<sup>69</sup> has been published to support the establishment of partnerships. Supplementary advice has also been issued on how partnership should inform local approaches to the integration of children's services. The guidance and supplementary advice recognise that one model does not fit all, and that approaches will develop to fit local circumstances.

The Scottish Executive 2003 review of speech and language therapy, physiotherapy and occupational **therapy services** for children, called on service providers to develop new methods of working in non-traditional and inclusive settings, such as mainstream schools and nurseries and other community settings. Other recommendations called on local authorities and NHSScotland to develop integrated approaches to the provision of therapy and other related interventions for children. Work is being undertaken to address the review's recommendations and this will dovetail with the Act.

The Scottish Executive publication, *Health for All Children (Hall 4)*, provides guidance on **health screening** based on recommendations made by the Royal College of Paediatrics and Child Health. It sets *Hall 4* in the context of other Scottish policies to promote effective and integrated provision of universal and targeted services for children and families, and describes the activity needed for implementation at national and local levels. The guidance provides a holistic approach to child health surveillance and screening in Scotland. It also describes initiatives that will inform effective child health promotion and surveillance.

The Scottish Executive guidance, *A Scottish Framework for Nursing in Schools*<sup>70</sup>, sets out the role of the school nursing team and standards for practice in **school medical services**. NHS Health Scotland is undertaking development work on a school health profiling tool that will inform the development of school health plans and, ultimately, the school planning process. This will inform school-based approaches to health improvement, including the activities of the school nursing service within each school. The role of the school nursing service will move away from a focus on routine surveillance, towards a combination of school population-focused health improvement, and addressing the individual health needs of vulnerable children. In accordance with the recommendations in both *Hall 4* and *A Scottish Framework for Nursing in Schools*, there should be a named nurse for each school, with access to a wider team of health support such as community children's nurses, paediatricians and therapists.

The Scottish Executive is developing a framework for children and young people's **mental health**. *Children and Young People's Mental Health: A Framework for Promotion, Prevention and Care* sets out a range of activities and approaches to support children and young people's mental health and wellbeing. The framework has been developed to support integrated approaches to children and young people's mental health, across mental health promotion, prevention of mental illness, and care and treatment for those with mental health problems. It highlights mental health promotion and stresses the importance of considering the child's global environment, recognising elements which support mental health and wellbeing as well as those factors which may increase the risk of mental health problems, including the potential impact of a parent's ill health on their child.

The framework promotes a ‘mainstream’ approach to mental health and wellbeing, which equips a range of health and other children’s services professionals with the basic skills to be able to support parents in developing a basic understanding of risk and protective factors that may affect their child’s mental health and wellbeing. To support this, NHS Education for Scotland has published a mental health competency framework for all those involved in supporting children, young people and their families. Education policy and practice already has a strong focus on promoting and supporting emotional wellbeing, and the **Health Promoting Schools** concept broadens this focus beyond the curriculum to a ‘whole school approach’.

## Children and families

The Scottish Executive has embarked upon a programme to reform **child protection** services following the Audit and Review of Child Protection, *It’s everyone’s job to make sure I’m alright*. The programme includes a *Children’s Charter*<sup>71</sup> and a *Framework for Standards*<sup>72</sup> for child protection. The charter sets out the support that the most vulnerable children have the right to expect. The framework sets out what children in Scotland can expect from professionals and agencies to ensure that they are adequately protected and their needs are met. The child protection reform programme is underpinned by a range of work across the Executive on integrated children’s services and early intervention strategies.

The Scottish Executive review of the **children’s hearings** system, *Getting It Right For Every Child*<sup>73</sup>, proposed that measures to improve the hearings system be linked to improvements in the wider network of children’s support services. There are concerns that children are not receiving support when they need it, and that many are being referred to the Children’s Reporter when more effective local action would be more appropriate. The Scottish Executive is consulting on phase 2 of the Hearings Review, including options to strengthen individual agency and collective responsibility for identifying and addressing children’s needs. This will link with, and build on, the work to develop an Integrated Assessment Framework, outlined previously, and with the developments underway within the child protection reform programme.

The joint Her Majesty’s Inspectorate of Education/Social Work Services Inspectorate inspection report, *Learning with Care*<sup>74</sup>, looked at the education of **children looked after** away from home by local authorities. It included specific recommendations for social work and educational services provided by local authorities. The additional support needs framework is relevant for the work of all professionals working with children who are looked after.

The Scottish Executive report, *Improving the Effectiveness of the Youth Justice System*<sup>75</sup>, established a set of national standards for Scotland's **youth justice** services. Every local authority must have a multi-disciplinary youth justice team to implement these standards and to achieve the national target of reducing the number of persistent offenders. The development of national standards for youth justice will take place in the context of integrated children's services at a national and a local level and the strategy for youth justice services will be incorporated in integrated children's services plans.

The Scottish Executive has published its response to *Hidden Harm – The Report of the Inquiry by the Advisory Council on the Misuse of Drugs*<sup>76</sup> which sets out the measures, either underway or in the planning stages, to tackle the problem across Scotland. In addition, to its response, the Executive has set up the Hidden Harm New Agenda Steering Group to oversee the implementation of the report's recommendations, but also to promote progression from joint planning of separate services to achieving more integrated service planning and delivery for children of substance misusing parents.

### Post-school education services

Following the report of the Beattie Committee, *Implementing Inclusiveness: Realising Potential*<sup>77</sup> (1999), the Scottish Executive endorsed the principle that inclusiveness should underpin all post-school education. Inclusiveness is about providing learning opportunities that give the best match to the needs of the individual. All **further education** colleges in Scotland continue to develop inclusive, learner-centred policies. The Scottish Executive has published *Partnership Matters* which provides guidance to local authorities, NHS Boards and voluntary organisations on supporting students with additional needs in further education. The guidance sets out the roles and responsibilities of all the agencies involved and encourages a partnership approach to cross-agency working. It recognises that young people may experience barriers to accessing and participating in learning, and that colleges and schools may be required to work together to plan for and prepare the young person for transition from school to post-school education.

As part of the commitment to providing learning opportunities that give the best match to the needs of the individual, the Executive has published a consultation paper, *Finding Practical Solutions to Complex Needs*<sup>78</sup>, about the arrangements for supported further education places and funding for students with complex needs. Further information is available in the resources section.

\*This information has been largely based on the *supporting children's learning: codes of practice*.<sup>79</sup>

## Annex D: Useful contacts and information

### ACE ADVOCACY

ACE Advocacy was started in January 2003, and provides information for people with learning disabilities about independent advocacy. The project is managed by ENABLE Scotland with a view to the project running independently in the future.

ACE Advocacy  
C/o ENABLE Scotland  
6th Floor  
7 Buchanan Street  
Glasgow  
G1 3HL

Telephone: 0141 225 1690

Email: [ace.advocacy@enable.org.uk](mailto:ace.advocacy@enable.org.uk)

### ADDITIONAL SUPPORT NEEDS TRIBUNAL FOR SCOTLAND

This website provides information about the tribunal.

Website: <http://www.asntscotland.gov.uk>

### AFASIC

AFASIC promotes understanding, acceptance, equal opportunities and inclusion of children and young people with speech and language impairments.

AFASIC  
1 Prospect III  
Gemini Crescent  
Dundee Technology Park  
Dundee  
DD2 1TY

Telephone: 01382 561891

Email: [afasicscotland@btopenworld.com](mailto:afasicscotland@btopenworld.com)

Website: <http://www.afasic.org.uk/>

**ASSESSMENT FOR LEARNING PROGRAMME**

This seeks to provide a streamlined and coherent system of assessment. It will ensure parents, teachers and other professionals have the feedback they need on pupils' learning and development needs.

Website: <http://www.ltscotland.org.uk/assess/texthome.asp>

**AUTISM ARGYLL**

Autism Argyll was formed in August 2000 by a group of parents to provide support and information to parents, carers and those affected by Autism Spectrum Disorders (ASD) living within Argyll and Bute.

Email: [alison.leask1@btinternet.com](mailto:alison.leask1@btinternet.com)

Website: <http://www.argyllcommunities.org/AUTISMARGYLL/>

**BARNARDO'S**

Barnardo's Scotland is working to improve the lives of almost 9,000 children, young people and their families each year. They deliver 61 services where they promote social inclusion in the face of disability, abuse, HIV/AIDS, family breakdown, poverty, educational breakdown, homelessness, alcohol or drug misuse.

Barnardo's Scotland  
235 Corstorphine Road  
Edinburgh  
EH12 7AR

Telephone: 0131 334 9893

Website: <http://www.barnardos.org.uk/scotland>

**THE CALL CENTRE**

The CALL Centre (Communication Aids for Language and Learning) provides specialist expertise in technology for children who have speech, communication and/or writing difficulties in schools across Scotland.

The CALL Centre  
University of Edinburgh  
Paterson's Land  
Holyrood Road  
Edinburgh  
EH8 8AQ

Telephone: 0131 651 6235/6236

Email: [info@callcentrescotland.org.uk](mailto:info@callcentrescotland.org.uk)

Website: <http://www.callcentre.education.ed.ac.uk/>

## **CAPABILITY SCOTLAND**

Capability Scotland is a leading disability organisation in Scotland. They provide a range of flexible services which support disabled people of all ages in their everyday lives.

ASCS (Advice Service Capability Scotland)  
11 Ellersly Road  
Edinburgh  
EH12 6HY

Telephone: 0131 313 5510  
Email: [ascscapability-scotland.org.uk](mailto:ascscapability-scotland.org.uk)  
Website: <http://www.capability-scotland.org>

## **CAREERS SCOTLAND**

Careers Scotland provide services, information and support to individuals of all ages and stages of career, planning and employers wanting to recruit and maintain a productive workforce.

Careers Scotland  
Headquarters  
150 Broomielaw  
Atlantic Quay  
Glasgow  
G2 8LU

National Telephone: 0845 8 502 502  
Telephone: 0141 228 2264/2489/2527  
Website: <http://www.careers-scotland.org.uk>

## **CENTRE FOR EDUCATION FOR RACIAL EQUALITY SCOTLAND (CERES)**

CERES works with the public, private and voluntary sectors across Scotland to raise awareness of race equality issues in education and advises on development and implementation of anti-racist policies and perspectives.

CERES  
Moray House Institute of Education  
Charteris Building  
Floor 2, Room 5  
Faculty of Education  
Holyrood Road  
Edinburgh EH8 8AQ

Telephone: 0131 651 6274  
Email: [ceres@ed.ac.uk](mailto:ceres@ed.ac.uk)  
Website: <http://www.education.ed.ac.uk/ceres/>

### **CHILDLINE SCOTLAND**

This helpline offers children and young people confidential advice on matters concerning them.

Childline Scotland  
18 Albion Street  
Glasgow  
G1 1LH

Telephone: 0870 336 2910

Helpline: 0800 1111

Website: <http://www.childline.org.uk/Scotland.asp>

### **THE CHILDREN'S COMMISSIONER**

The Commissioner keep an eye on what's happening in the Scottish and commissions and publishes research into issues that are important to children and young people. It provide an information and signposting service to adults, including families and people who work with children. The Commissioner is not responsible for investigating cases relating to the rights of and provision of services for individual children.

Scotland's Commissioner for Children and Young People

85 Holyrood Road

Edinburgh

EH8 8AU

Telephone : 0131 558 3733

Email: [enquiries@sccyp.org.uk](mailto:enquiries@sccyp.org.uk)

### **CHILDREN'S HEARING SYSTEM**

This website contains background information on Children's Panels and provides information on what happens in a Hearing.

Website: <http://www.childrens-hearings.co.uk/>

## **CHILDREN IN SCOTLAND**

Children in Scotland is the national agency for voluntary, statutory and professional organisations and individuals working with children and their families in Scotland. Children in Scotland exists to identify and promote the interests of children and their families through and for its members.

Children in Scotland  
Princes House  
5 Shandwick Place  
Edinburgh  
EH2 4RG

Telephone: 0131 228 8484

Email: [info@childreninscotland.org.uk](mailto:info@childreninscotland.org.uk)

Website: <http://www.childreninscotland.org.uk>

## **COMMISSION FOR RACIAL EQUALITY (SCOTLAND)**

Commission for Racial Equality (Scotland)

The Tun  
12 Jackson's Entry  
off Holyrood Road  
Edinburgh  
EH8 8PJ

Telephone: 0131 524 2000

Email: [Scotland@cre.gov.uk](mailto:Scotland@cre.gov.uk)

Website: <http://www.cre.gov.uk>

## **CONTACT A FAMILY SCOTLAND**

This national organisations offers information and support to families who care for children with any disability or additional support need and can link the families of children with rare of specific syndromes.

Contact a Family Scotland  
Norton Park  
57 Albion Road  
Edinburgh  
EH7 5QY

Telephone: 0131 475 2608

Email: [Scotland@cafamily.org.uk](mailto:Scotland@cafamily.org.uk)

Website: <http://www.cafamily.org.uk/scotland/>

### **DISABILITY RIGHTS COMMISSION**

The Disability Rights Commission (DRC) is an independent body established in April 2000 by Act of Parliament to stop discrimination and promote equality of opportunity for disabled people. The DRC works with disabled people, employers and service providers to find practical solutions for everyone.

DRC Helpline  
FREEPOST MID02164  
Stratford-upon-Avon  
CV37 9BR

Telephone: 08457 622 633  
Textphone: 08457 622 644  
Website: <http://www.drc.org.uk>

### **DOWN'S SYNDROME SCOTLAND**

Down's Syndrome Scotland aims to improve the quality of life for everyone in Scotland with Down's syndrome.

Down's Syndrome Scotland  
158/160 Balgreen Road  
Edinburgh  
EH11 3AU

Telephone: 0131 313 4225  
Email: [info@dsscotland.org.uk](mailto:info@dsscotland.org.uk)  
Website: <http://www.dsscotland.org.uk>

### **EARLY YEARS ONLINE – LEARNING & TEACHING SCOTLAND**

This provides up-to-date information of what is happening in early years education in Scotland, with news and events and a discussion forum.

Early Years Online Team  
Learning and Teaching Scotland  
The Optima  
58 Robertson Street  
Glasgow  
G2 8DU

Telephone: 08700 100 297  
Email: [enquiries@LTScotland.org.uk](mailto:enquiries@LTScotland.org.uk)  
Website: <http://www.ltscotland.org.uk/earlyyears/>

**EDUCATION LAW UNIT – GOVAN LAW CENTRE**

The Education Law Unit works in partnership with schools, education authorities, parents' groups and charities to make pupils' rights and parents' rights in education a reality.

Govan Law Centre  
47 Burleigh Street  
Govan  
Glasgow  
G51 3LB

Telephone: 0141 445 1955

Email: [advice@edlaw.org.uk](mailto:advice@edlaw.org.uk)

Website: <http://www.govanlc.com/index.html>

**ENABLE SCOTLAND**

ENABLE Scotland believes that children and adults with learning disabilities have the same rights as anyone else to lead full and active lives in their local communities. ENABLE Scotland helps people to do this by campaigning, providing services, supporting people to do things in new and innovative ways, and by helping children, young people and adults to have a say in decisions which affect them.

ENABLE Scotland  
6th Floor  
7 Buchanan Street  
Glasgow  
G1 3HL

Telephone: 0141 226 4541

Email: [enable@enable.org.uk](mailto:enable@enable.org.uk)

Website: <http://www.enable.org.uk/>

## **ENQUIRE**

Enquire is the Scottish advice and information service for additional support for learning. It is managed by Children in Scotland and is funded by the Scottish Executive. The service is available to parents and carers of children and young people with additional support needs, to children and young people themselves, and to professionals working with them. Enquire offers advice and information, training and talks, produces a range of free publications and has a legal subscription service.

Enquire  
Children in Scotland  
Princes House  
5 Shandwick Place  
Edinburgh  
EH2 4RG

Helpline: 0845 123 2303  
Email: [info@enquire.org.uk](mailto:info@enquire.org.uk)

## **EPILEPSY SCOTLAND**

This service aims to improve the quality of life for people with epilepsy and their families in Scotland.

Epilepsy Scotland  
48 Govan Road  
Glasgow  
G51 1JL

Telephone: 0141 427 4911  
Email: [enquiries@epilepsyscotland.org.uk](mailto:enquiries@epilepsyscotland.org.uk)  
Website: <http://www.epilepsyscotland.org.uk/epilepsy>

## **FAIRBRIDGE IN SCOTLAND**

Fairbridge offer support to young people living in deprived areas through a combination of long-term personal support and challenging activities to give them a route back into mainstream society.

Fairbridge in Scotland  
Norton Park  
57 Albion Road  
Edinburgh  
EH7 5QY

Telephone: 0131 475 2303  
Email: [fis@fairbridgescot.org.uk](mailto:fis@fairbridgescot.org.uk)  
Website: <http://www.fairbridge.org.uk/>

## **EQUITY IN EDUCATION**

The aim of Equity in Education is to improve educational and social incomes for children and young people, in particular those with additional support needs.

Equity in Education  
76 High Street  
Peebles  
EH45 8SW

Telephone: 01721 729326

Website: <http://www.equityineducation.org/>

## **HOME-START**

Home-Start is the UK's leading family support charity. Through a network of more than 12,000 trained parent volunteers, they support thousands of parents struggling to cope. The families need support for many reasons including post-natal illness, disability, bereavement, the illness of a parent or child, or social isolation.

Website: <http://www.homestart.org.uk/>

## **ISEA (INDEPENDENT SPECIAL EDUCATION ADVICE) (SCOTLAND)**

This organisations provides information, advice and support, including advocacy/representation, to parents and carers of children/young people with additional support needs.

ISEA  
164 High Street  
Dalkeith  
EH22 1AY

Telephone: 0131 454 0096 (Advocacy Project: 0131 454 0144)

## **LINKING EDUCATION AND DISABILITY**

LEAD provides guidance to physically disabled young people (16+) and adults requiring access to education and lifelong learning.

LEAD  
Queen Margaret University College  
36 Clerwood Terrace  
Edinburgh  
EH12 8TS

Telephone: 0131 317 3439

Email: [enquiries@lead.org.uk](mailto:enquiries@lead.org.uk)

Website: <http://www.lead.org.uk>

### **NATIONAL AUTISTIC SOCIETY**

The National Autistic Society exists to champion the rights and interests of all people with autism and Asperger's Syndrome and to ensure that they and their families receive quality services appropriate to their needs.

National Autistic Society Scotland  
Central Chambers  
1st Floor  
109 Hope Street  
Glasgow  
G2 6LL

Telephone: 0141 221 8090  
Email: [scotland@nas.org.uk](mailto:scotland@nas.org.uk)  
Website: <http://www.nas.org.uk>

### **NATIONAL CENTRE FOR AUTISM STUDIES**

The National Centre for Autism (NCAS) was established in November 2003, and is located in the University of Strathclyde Faculty of Education. They aim to provide opportunities for the collaboration and sharing of information in the field of autism spectrum disorders (ASD), including education and training, practice issues and research.

Telephone: 0141 950 3234  
Enquiries to: [margaret.ritchie@strath.ac.uk](mailto:margaret.ritchie@strath.ac.uk)  
Website: <http://www.strath.ac.uk/autism-ncas/home.html>

### **NHS EDUCATION FOR SCOTLAND (NES)**

NHS Education for Scotland aims to provide better patient care by designing, commissioning, quality assuring and, where appropriate, providing education, training and lifelong learning for the NHS workforce in Scotland.

Central Offices:  
2nd Floor  
Hanover Buildings  
66 Rose Street  
Edinburgh  
EH2 2NN

Telephone: 0131 225 4365

22 Queen Street  
Edinburgh  
EH2 1JX

Telephone: 0131 226 7371  
Email: [enquiries@nes.scot.nhs.uk](mailto:enquiries@nes.scot.nhs.uk)  
Website: <http://www.nes.scot.nhs.uk>

**NHS HELPLINE SCOTLAND**

This helpline offers information on health services, practices and procedures.

NHS Helpline Scotland  
Network Scotland  
Ruthven Lane  
The Mews  
Glasgow  
G12 8NT

Helpline: 0800 22 44 88

**PAMIS**

PAMIS is an organisation in Scotland working with people with profound and multiple learning disabilities, their family carers and professionals who support them.

PAMIS  
Springfield House  
15/16 Springfield  
University of Dundee  
Dundee  
DD1 4JE

Telephone: 01382 345 154

Email: [pamis@dundee.ac.uk](mailto:pamis@dundee.ac.uk)

Website: <http://www.dundee.ac.uk/pamis>

**PARENTLINE SCOTLAND**

Parentline is a confidential telephone helpline run by Children 1st providing support to parents and carers in talking through any concerns relating to parenting issues.

Parentline Scotland  
83 Whitehouse Loan  
Edinburgh  
EH9 1AT

Telephone: 0131 446 2333

Freephone: 0808 800 22 22

Website: <http://www.children1st.org.uk>

### **PARIS (Public Autism Resource & Information Service)**

This is a new online services provided by the National Autistic Society. It draws from a UK-wide database of diagnostic services, schools, support groups, training courses, residential and day services. PARIS is designed to help people with autism and Asperger's Syndrome, their families and the people who work with them professionally to find out more about the services available to them.

PARIS Department  
The National Autistic Society  
Castle Heights  
72 Maid Marian Way  
Nottingham  
NG1 6BJ

Telephone: 0115 911 3360

Email: [Paris@nas.org.uk](mailto:Paris@nas.org.uk)

Website: <http://www.info.autism.org.uk>

### **PARTNERS IN ADVOCACY**

Partners in Advocacy is an advocacy organisation for adults, young people and children with learning disabilities, and provide services in Edinburgh, Glasgow, West Lothian, Dundee and Midlothian. Their work is based on the principles of human rights and independent advocacy.

Partners in Advocacy  
Central Office  
Unit 17  
John Cotton Business Centre  
10 Sunnyside  
Edinburgh  
EH7 5RA

Telephone: 0131 478 7723

Email: [admin@partnersinadvocacy.org.uk](mailto:admin@partnersinadvocacy.org.uk)

**PEOPLE FIRST (SCOTLAND)**

People First (Scotland) represents the interests of people with learning disabilities in Scotland. They develop and support self-advocacy for people with learning disabilities through the creation of and support to independent local groups in Scotland which are affiliated to People First (Scotland).

People First (Scotland)  
77-79 Easter Road  
Edinburgh  
EH7 5PW

Telephone: 0131 478 7707  
Email: [P1st@btconnect.com](mailto:P1st@btconnect.com)  
Website: <http://www.peoplefirstscotland.com>

**PLAYBACK TRUST**

The Playback Trust is aimed at young people between 12-18 years of age who have physical disabilities. The young people at Playback play an active part in creating an activity programme. The programme is designed to enable young people to play an active part in their community.

Telephone: 0131 453 4889  
Email: [maybaillie@playbacktrust.org](mailto:maybaillie@playbacktrust.org)  
Website: [www.playbacktrust.org](http://www.playbacktrust.org)

**POSITIVE PARENTING**

Positive Parenting specialises in the support of parents and those who work with them.

2a South Street  
Gosport  
Hampshire  
PO12 1ES

Telephone: 023 9252 8787  
Email: [info@parenting.org.uk](mailto:info@parenting.org.uk)  
Website: <http://www.parenting.org.uk/Default.aspx>

**PRINCE'S TRUST**

The Prince's Trust enables young people to come together and make a contribution to their local community while developing their own self-confidence and motivation.

Telephone: 0141 204 4409  
Website: <http://www.princes-trust.org.uk>

## **RATHBONE**

Rathbone provides a wide range of national services including programmes to support young people who have fallen out of mainstream education, special programmes for young people who have been excluded or who are in danger of being excluded from school, and a network of independent living centres for people with special needs helping them gain the skills and the confidence they need to live independently in the community.

To contact a specific Rathbone Centre directly, go to the 'Where Are We' section of the website.

Rathbone Head Office  
Churchgate House  
56 Oxford Street  
Manchester  
M1 6EU

Telephone: 0161 236 5358  
Minicom: 0161 238 6345  
Email: [info@rathboneuk.org](mailto:info@rathboneuk.org)  
Website: <http://www.rathbonetraining.co.uk/>

## **SCOTTISH CHILD LAW CENTRE**

54 East Crosscauseway  
Edinburgh  
EH8 9HD

Freephone (for under 18s): 0800 328 8970  
Telephone: 0131 667 1713  
Email: [enquiries@sclc.org.uk](mailto:enquiries@sclc.org.uk)  
Website: <http://www.sclc.org.uk/>

## **SCOTTISH CONSORTIUM FOR LEARNING DISABILITY (SCLD)**

SCLD is an organisation set up to help people make the changes set out in *The same as you?*

Scottish Consortium for Learning Disability  
Unit 16  
Adelphi Centre  
12 Commercial Road  
Glasgow  
G5 0PQ

Telephone: 0141 418 5420  
Website: <http://www.sclld.org.uk>

## **SCOTTISH INDEPENDENT ADVOCACY ALLIANCE**

The Scottish Independent Advocacy Alliance (SIAA) promotes, supports and defends the principles and practice of independent advocacy across Scotland. SIAA was set up as a result of the work undertaken by its predecessor Advocacy 2000, a 3-year project set up to look at the needs of the Advocacy Movement in Scotland, and how these could be supported in the future.

Scottish Independent Advocacy Alliance  
138 Slateford Road  
Edinburgh  
EH14 1LR

Telephone: 0131 455 8183  
Email: [enquiry@siaa.org.uk](mailto:enquiry@siaa.org.uk)  
Website: <http://www.siaa.org.uk>

## **SCOTTISH SOCIETY FOR AUTISM**

The Scottish Society for Autism was established in 1968 and works together with people with Autism Spectrum Disorder (ASD), their families, carers and other organisations to provide quality services and training in education and care; influence policy and practice to ensure the best education, care, support and opportunities; and to raise public awareness about ASD and how it affects the lives of families in Scotland.

Scottish Society for Autism  
Hilton House  
Alloa Business Centre  
The Whins  
Alloa  
FK10 3SA

Telephone: 01259 720044  
Email: [info@autism-in-scotland.org.uk](mailto:info@autism-in-scotland.org.uk)  
Website: <http://www.autism-in-scotland.org.uk>

## **SCOTTISH YOUTH PARLIAMENT**

The SYP aims to be a collective national youth voice for all young people in Scotland.

Scottish Youth Parliament  
Rosebery House  
9 Haymarket Terrace  
Edinburgh  
EH12 5EZ

Telephone: 0131 313 2488  
Website: <http://www.scottishyouthparliament.org.uk>

### **SENSE SCOTLAND**

Sense Scotland are a service providing organisation which is also engaged in policy development for children and adults with complex support needs because of deafblindness or sensory impairment, learning disability or physical disability. Sense Scotland also provide communication and innovative support services for people who are marginalised because of challenging behaviour, health care issues and the complexity of their support needs.

Sense Scotland  
43 Middlesex Street  
Kinning Park  
Glasgow  
G41 1EE

Telephone: 0141 429 0294  
Email: [info@sensescotland.org.uk](mailto:info@sensescotland.org.uk)  
Website: <http://www.sensescotland.org.uk>

### **SKILL SCOTLAND**

This service promotes opportunities to empower young people and adults with disabilities to realise their potential in further and higher education, training and employment.

SKILL Scotland  
Norton Park  
57 Albion Road  
Edinburgh  
EH7 5QY

Telephone: 0131 475 2348  
Email: [admin@skillscotland.org.uk](mailto:admin@skillscotland.org.uk)  
Website: <http://www.skill.org.uk>

### **SPECIAL NEEDS INFORMATION POINT**

14 Rillbank Terrace  
Edinburgh  
EH9 1LN

Telephone: 0131 536 0583  
Textphone: 0131 536 0360  
Email: [snip@btinternet.com](mailto:snip@btinternet.com)  
Website: <http://www.snipinfo.org/>

## **SURE START CHILDCARE LINK**

The Government launched the ChildcareLink Helpline and website in December 1999 as part of the National Childcare Strategy. This strategy aims to help people back into the workplace by removing the childcare barrier. The ChildcareLink service is funded by the Department for Education and the Scottish Executive.

Opportunity Links  
Trust Court  
Vision Park  
Histon  
Cambridge  
CB4 9PW

Email: [childcarelink@opp-links.org.uk](mailto:childcarelink@opp-links.org.uk)

Website: <http://www.childcarelink.gov.uk/index.asp>

## **UPDATE**

UPDATE is Scotland's National Disability Information Service. They provide information, resources and other supporting services to enable any type of organisation to provide reliable, relevant and up-to-date disability information. They have also taken over from Direct Payments Scotland to provide information and advice about receiving direct payments for self-directed care in Scotland.

UPDATE  
27 Beaverhall Road  
Edinburgh  
EH7 4JE

Telephone: 0131 558 5200

Minicom: 0131 558 5201

Email: [info@update.org.uk](mailto:info@update.org.uk)

Website: <http://www.update.org.uk/>

### **WHO CARES? SCOTLAND**

Who Cares? Scotland is an independent organisation who work with children and young people with experience of being looked after in Scotland. They provide a range of services including advocacy, advice, information and support.

Who Cares? Scotland  
5 Oswald Street  
Glasgow  
G1 4QR

Telephone: 0141 226 4441

Email: [enquiries@whocaresscotland.org](mailto:enquiries@whocaresscotland.org)

Website: <http://www.whocaresscotland.org/>

### **YOUNG SCOT**

The national youth information and discount service in Scotland.

Young Scot  
Rosebery House  
9 Haymarket Terrace  
Edinburgh  
EH12 5EZ

Telephone: 0131 313 2488

Website: <http://www.youngscot.org>

### **YOUTH SCOTLAND**

This organisations supports, develops and improves the range and quality of informal, educational, social and leisure opportunities available for young people in Scotland.

Telephone: 0131 229 0339

Website: <http://www.youthscotland.org.uk>

### **YOUTHLINK SCOTLAND**

This aims to support the development of accessible, high quality youth work services which promote the well-being and development of young people.

Youthlink Scotland  
Rosebery House  
9 Haymarket Terrace  
Edinburgh  
EH12 5EZ

Telephone: 0131 313 2488

Website: <http://www.youthlink.co.uk>

## Glossary

<b>Action plan</b>	A structured plan which sets out timescales, responsibilities and services required to meet a child's or young person's assessed needs (see entries for integrated action plan, personal learning planning, individualised educational programme, co-ordinated support plan and looked after care plan).
<b>Additional support</b>	Provision which is additional to, or otherwise different from, the educational provision made generally by an education authority for children and young people of the same age in schools (other than special schools) under the management of the education authority.
<b>Appropriate agency</b>	An agency, or any person, specified in the Act, or by regulation, as having duties under the Act. Other agencies, whether statutory or voluntary, may work with local authorities to support a child's or young person's learning without being under a statutory duty.
<b>Assessment</b>	An ongoing process of gathering, structuring and making sense of information about a child or young person, and their circumstances, in order to inform decisions about the actions necessary to maximise their potential.
<b>Advocate/ Advocacy</b>	Someone who helps people with learning disabilities to say what it is they need and to make their own decisions. See citizen advocate and self-advocate.
<b>Asperger's syndrome</b>	This is a type of autism (see below) that some people of average intelligence and language ability have. They find it particularly difficult to understand what other people think and this makes it hard for them to communicate and act appropriately.
<b>Autism Spectrum Disorder (ASD)</b>	A lifelong, complex condition resulting in mild to severe social, language and communication, and thought and behavioural impairments.

<b>Carer</b>	Includes parents and other people with parental responsibilities, for example, public foster carers, relatives and friends who are caring for children and young people under supervision requirements, and close relatives, such as siblings or grandparents caring for children who are not looked after or are under home supervision requirements. (see also parent).
<b>Challenging behaviour</b>	A term used to describe when someone is acting in a way that might do themselves or others harm. People who care for these people are 'challenged' to stop the harm. That is why we call it 'challenging behaviour'.
<b>Citizen advocate</b>	An 'unpaid' volunteer who is independent of the services, a person with learning disabilities receives. This advocate represents the needs of the person and supports them to make sure they get their rights.
<b>Commissioning</b>	Deciding what services are needed and then getting someone to provide these by signing a contract.
<b>Complex needs</b>	This describes the needs a person has over and above their learning disability. For example, extra physical or mental health problems, challenging behaviour or offending behaviour.
<b>Co-ordinated support plan</b>	A statutory strategic planning document to co-ordinate the provision of services for those children and young people, who meet the criteria, to help them work towards their agreed long-term educational objectives.
<b>Direct payments</b>	Local authorities giving people money to buy their own social care services so that they have more say in how their needs are met. Also known as 'self-directed care'.
<b>Dispute resolution</b>	The involvement, under regulations supporting the ASL Act, of an independent adjudicator to review a disagreement between parents, or a young person, and an education authority, over the exercise by the authority of any of its duties or functions under the Act, and to make recommendations for parties aimed at resolving the dispute.

<b>Dual diagnosis</b>	Where someone has both a learning disability and mental health problems.
<b>Education authority</b>	In legal terms, education authority and local authority are both defined as a council constituted under section 2 of the Local Government etc (Scotland) Act 1994. The code refers to an education authority when considering a local authority's educational functions; and to a local authority when referring to functions other than educational ones, such as social work services.
<b>Individualised Educational Programme</b>	Written document which outlines the steps to be taken to help children and young people who have additional support needs to achieve specified learning outcomes.
<b>Integrated Assessment Framework</b>	A common means for all agencies and professionals to assess children's and young people's needs and to share information about them in order to ensure that interventions at any level lead to improvements in the child's or young person's life.
<b>Learning difficulty</b>	Pre-school and school-age children are usually described as having a learning difficulty rather than a disability when they have special educational needs that need extra or different approaches to the way they are taught.
<b>Looked after child or young person</b>	The Children (Scotland) Act 1995 has a statutory definition of a looked after child. These are children or young people who are accommodated by the local authority; or are subject to one of the specified orders, including a child protection order; a parental responsibilities order; or are subject to a supervision requirement whilst living at home.
<b>Mainstream</b>	Generally available to all members of the community.
<b>Mediation</b>	A voluntary process whereby an independent third party seeks to enable parties to a disagreement to reach an agreed resolution of their differences.
<b>Multi-disciplinary</b>	Where more than one professional from different disciplines within the same agency work together (e.g. speech therapist and health visitor).

<b>Multi-agency</b>	Where professionals from different agencies work together (e.g. teachers and health or social workers).
<b>Multiple disability needs</b>	Where someone needs help with several aspects of life which may include health, education, leisure, financial or housing support and being part of the community.
<b>Natural supports</b>	People who help those with learning disabilities like family and friends and are not paid to do this.
<b>Personal learning planning</b>	Process by which children, young people and parents are involved in discussions with the school about the goals of learning, including those for personal development. Its focus is on supporting dialogue and ultimately about engaging children and young people in their own learning.
<b>Post school education</b>	The range of education that takes place after school leaving age. It may include further education, community education, higher education, adults going back to school, other kinds of informal education and vocational training.
<b>Profound disability needs/ Profound and Multiple Learning Disability (PMLD)</b>	A term used to describe someone who has a very severe degree of learning disability which may be associated with complex needs. For example, this could include feeding difficulties, physical disabilities or sensory impairment.
<b>School age</b>	Generally from the age of 5 to 16 years.
<b>Self-advocacy</b>	Where people with learning disabilities promote their needs and wishes for themselves.
<b>Sensory impairment</b>	A loss of sight or hearing or both.
<b>Social inclusion</b>	Helping people to feel and be part of the society in which they live. They are 'socially included'.

<b>Special school</b>	a school or any class or other unit forming part of a public school which is not itself a special school, the sole or main purpose of which is to provide education specially suited to the additional support needs of children or young people selected for attendance at the school, class or (as the case may be) unit by reason of those needs.
<b>Supporter</b>	Someone chosen by the parent or young person to be present at any discussions with the authority or at the tribunal for the purpose of supporting them in the course of those discussions.
<b>Targeted services</b>	Services which are designed to help specific children and young people for particular needs, e.g. social work, the Reporter, police, a whole range of voluntary sector provision.
<b>Transitions</b>	Refers to changes in education, for example, starting nursery school, moving from primary to secondary school, transferring schools within or outwith an education authority's area.
<b>Universal services</b>	Services which all children and young people have access to throughout their childhood, e.g. health and education provision.
<b>Young carer</b>	Children and young people who provide care to a family member.
<b>Young people</b>	The code uses this term to refer to those young persons over school age (generally over 16 years) who are not yet 18 years of age, as per the definition in the 1980 Act.

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