

# Report of the National Review of Services for Disabled Children

# **Report of the National Review of Services for Disabled Children**

© Crown copyright 2011

ISBN: 978-1-78045-053-7 (web only)

The Scottish Government  
St Andrew's House  
Edinburgh  
EH1 3DG

Produced for the Scottish Government by APS Group Scotland  
DPPAS11350 (02/11)

Published by the Scottish Government, February 2011

# **REPORT OF THE NATIONAL REVIEW OF SERVICES FOR DISABLED CHILDREN**

## **Introduction**

The national review of services for disabled children was undertaken jointly by Scottish Government, the Convention of Scottish Local Authorities (COSLA) and the For Scotland's Disabled Children (fSDC) Liaison Project to provide a strategic assessment of the children's disability landscape. This report and its accompanying plan for action mark the first stage in a longer process; the next stage is the implementation by all relevant partners of actions flowing from the report. This is a new and much needed piece of work. It originates in the commitment given in the Scottish Parliament debate on the Public Services Reform Bill in March 2010 to undertake a broad strategic review of all aspects of services for disabled children. There has been no recent comparable attempt in Scotland at a review across services for disabled children.

The importance of the agenda set out in this report is clear. Services for disabled children impact directly on many thousands of children, young people and their families, and when delivered well can have a transformative effect on the lives of disabled children and their siblings. The report feeds directly into this vision of better outcomes for disabled children; similarly, its actions support the delivery of key elements in the Scottish Government's performance framework, and disabled children and young people's statutory rights to equal treatment and equality of services under equality legislation and public authorities' equality duties. It is the overarching purpose of the report to assess the current state of services for disabled children in order to begin the process of real change.

In a short space of time the lead partners behind the review brought together an expert steering group to consider how it should be taken forward. This group included national and local government, health, the voluntary sector, parents and academic researchers specialising in work with disabled children. (Full membership of the review group is set out in Annex A.) The remit of the group was to advise Scottish Ministers, COSLA and fSDC on:

- The key needs of families with disabled children, and of disabled children themselves
- The current configuration of services for disabled children, how well families' and children's needs are met, and whether gaps can be identified
- Workforce/ training issues around disabled children and families of disabled children, and specific issues around children's disability to inform wider work on workforce development within children's services
- Short, medium and longer-term actions to deliver practical improvements to the well-being of disabled children, their siblings, parents and carers.

## Background to the Review – Definitions and Statistics

### *Definitions*

The Equality Act 2010, building on the Disability Discrimination Act, provides one useful definition of disability:

A person has a disability ... if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.

There are in addition definitions of disability in relation to children and young people, and statistical categories, which provide different approaches to classifying disability. For example, it is important to maintain distinctions between terms such as ‘disabled children’ and ‘children with additional support needs’. These categories certainly overlap, but are not interchangeable. Enquire (the Scottish advice service for additional support for learning) provides a straightforward factsheet explaining definitions and the statutory provisions applying to both categories at <http://enquire.org.uk/publications/factsheets/education-and-disability-rights>.

Enquire also provides the following definition of additional support needs in the context of the ASL Acts:

‘Additional support for learning’ means giving children extra help or support to help them get the most out of their education and reach their fullest potential. A child or young person is said to have ‘additional support needs’ if they need more – or different support – to what is normally provided in schools or pre-schools to children of the same age.

It doesn’t just apply to children who have long-term learning difficulties or disabilities. Children can need support for many reasons. Some may need a lot of support all the way through school. Others will only need a small amount for a short time.

There are many reasons why a child might need additional support for learning ... It is not possible to list all the reasons because it will depend on the child. Children are affected by things in different ways – one child who has lost a family member may struggle at school but another will not.

One issue that complicates the area of definitions is how best to deliver support when the spectrum of definitions of disability and impairment is so wide and potentially overlapping. There is a particular issue with the breadth of definitions within education, where it is unclear when the responsibility for supporting all children under Curriculum for Excellence becomes a requirement for *additional* support. This is particularly true when a child is at the mild or developing part of the spectrum.

## *Statistics*

Drawing on the Pupils in Scotland census 2009, the recent baseline survey carried out by fSDC – *Setting the Scene* – suggests that there are nearly 45,000 young people with additional support needs in Scotland; of these, nearly 11,500 are declared or assessed as disabled; 7,500 are not in mainstream schools; and 300 are in grant-aided special schools. The pupil census also shows that of those who have been identified as having special needs,

- 9,232 have a learning disability
- 1,340 have a visual impairment
- 1,007 have a hearing impairment
- 43 are deaf-blind
- 3,103 have physical or motor impairment
- 2,377 have a physical health problem
- 275 have a mental health problem.

Of course, some individuals will appear in more than one category, and it is important to note that the census in 2009 focused on pupils with an individualised education programme (IEP) and/or Co-ordinated Support Plan (CSP). From 2010 onwards the collection will also include pupils who need additional support for learning but have not been formally assessed as requiring an IEP or CSP. This reflects the interest and importance that users of these statistics apply to having information on the wide spectrum children requiring additional support for learning, and not just children and young people who have a formal plan.

*Setting the Scene* also adds data on the 28,190 recipients of Disability Living Allowance between the ages of 5 and 17 in Scotland. Disability Living Allowance is payable in respect of those with complex needs and is therefore a potential indicator of the numbers of disabled young people, and thus a likely useful part of future work to predict and plan services for disabled children with complex needs.

It is also interesting to note that a recent HMIE report on implementation of the ASL Act found significant discrepancies between the pupil census figures and education authorities' own reports, underscoring the ongoing difficulty of achieving definitive information in this area.

The Scottish Household Survey (2009) suggests that 5% of 0-15 year olds have a disability and/or long-term illness that limits their daily activity. The Scottish Health Survey (2009) reports that 15% of children aged 0-15 had a long-term condition, 9% non-limiting, and 6% were limiting. Boys were more likely than girls to report a long-term condition (17% compared with 14%), and although small this difference was statistically significant.

If a child or young person is considered to have 'additional support needs' by a health professional (for instance a GP, health visitor or school nurse) they can be referred for inclusion on the Support Needs System (SNS) which was established in 1993 and has now been implemented in 11 NHS Boards across Scotland. However, because the SNS has not been implemented fully across all NHS Boards it cannot be used as a

direct indication of the prevalence of particular conditions in the wider population. It can however give an indication of the types of impairment which are most commonly referred by health professionals.

There is also likely to be a number of disabled children who are not captured by either education or health systems. This therefore suggests that while valuable data on disabled children exist in a variety of places, there remains no known single collation of data about the number, or nature of assessments of disabled children and young people in Scotland. While it is clearly difficult to arrive at any definitive figure, it is also important to recognise that different users may have – and continue to have – different needs for certain subsets of data.

Definitions and statistics matter if we are to plan and apportion finances and services both well and seamlessly. This is true both in terms of services for children and young people and in planning for the future support needs of disabled adults. Definitions of disabled children and young people will evolve as our understanding of the landscape of services evolves, and as the needs of children change. A key example of this is children with exceptional healthcare needs and higher levels of impairment who are now surviving because of technological and medical advances.

The system will also need to incorporate changes in the incidence of conditions associated with disability, such as foetal alcohol syndrome, into future planning. New and beneficial developments in technology can also lead to increased levels of hospitalisation or demand for other services, such as home ventilation. At a time of pressure on public finances, these issues will lead to challenges around how and for whom we prioritise services. Within this context, regularly reviewed Children's Services Plans can provide a basis for estimating the additional service providers might build into their planning. *Setting the Scene* found that some children's services plans provided no published date for their review, and more regular reviews would be beneficial in this process.

In addition, the 2010 SWIA report *Improving Social Work in Scotland* noted that:

...over 80% of care plans for children were regularly reviewed. Almost all care plans for children who were looked after away from home were regularly reviewed (92%) but only 71% of care plans for children with disabilities were regularly reviewed.

Whilst definitions are subject to ongoing debate and interpretation, progress is being made, both in terms of data on disability and on additional support needs. The 2011 census will gather more information than previous censuses about disability within households and provide a systematic means of gathering first-hand data about the issue. The Census (27 March 2011) will allow a much more detailed breakdown of 'long-term health conditions' using the following question: "Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months?" The listed conditions are:

- Deafness or partial hearing loss
- Blindness or partial sight loss
- Learning disability (e.g. Down's Syndrome)

- Learning difficulty (e.g. dyslexia)
- Developmental disorder (e.g. ASD or Asperger's Syndrome)
- Physical disability
- Mental health condition
- Long-term illness, disease or condition
- Other.

Another question, asking respondents if they have any long-term illness, health problem or disability which limits their daily activities or the work they can do, has been slightly amended since the 2001 census, to distinguish between limiting 'a lot' or 'a little'.

Within education, an improved basis for gathering information about types and costs of education-based support for children and young people will be available in future. From 2011/12, in accordance with the Education (Additional Support for Learning) (Scotland) Act 2009, information will be collected from education authorities and published on an annual basis by Scottish Ministers. This information will include the number of children and young people with additional support needs for whose school education the authority is responsible, the main factors giving rise to those additional support needs, the types of support provided and the cost of providing that support. Information obtained under this legislation has wider application and benefits beyond education.

## **Outcomes and Indicators**

The Scottish Government's performance framework sets out a number of national outcomes. Within this framework, government and public services are focused on shared ambitions, expressed at national level through the National Performance Framework and reflected locally. Many of these national outcomes are of vital relevance to the lives of disabled children and young people. They include:

- National Outcome 5 – our children should have the best start in life and be ready to succeed
- National Outcome 8 – improving the life chances for children, young people and families at risk
- National Outcome 4 – our young people should become confident individuals, effective contributors, responsible citizens, successful learners.

Other National Outcomes relating to inequalities and public services are also relevant. Children's rights under the UN Convention are a guiding principle in the provision of services. There is also a key synergy between children's disability issues and the Well-being Indicators which form a central part of *Getting it right for every child*, Scottish Government's approach to work with all children and young people which seeks to streamline systems and processes to focus on the needs of the child. These eight indicators set out all that children should be:



- Safe – protected from abuse, neglect or harm at home, at school or in the community
- Healthy – having the highest attainable standards of health and access to healthcare
- Achieving – being supported and guided in their learning and development of their skills, confidence and self-esteem
- Nurtured – having a nurturing place to live, with additional help if needed
- Active – having opportunities to take part in activities such as play, recreation and sport
- Respected – having the opportunity, along with carers, to be heard and involved in decisions which affect them
- Responsible – having opportunities to play active and responsible roles in their schools and communities
- Included – having help to overcome social, educational, physical and economic inequalities and being accepted as part of the community in which they live and learn.

The review group concluded that if disabled children and young people are to fully identify with these indicators, there is a need for a more systematic plan of action to enable the necessary changes to systems, practice and culture which will deliver these goals. Two recent inspectorate reports highlight where such high-level aspirations should lie.

The November 2010 report by Her Majesty’s Inspectorate of Education, *Review of the Additional Support for Learning Act: adding benefits for learners* reviewed the workings of the Act with particular reference to looked after children and learners with hearing or visual impairment, or mental health issues. The review found that there are positive signs that the Act, alongside Curriculum for Excellence, More Choices, More Chances and *Getting it right for every child*, is contributing to an increased sense of shared responsibility for identifying learning needs; and that, where GIRFEC is a well established approach, it has a positive impact on joint working. The report identified issues which should be addressed in order to achieve the best for children and young people and made recommendations. One conclusion was that “there is also scope to improve the ways in which, at national and authority level, information in relation to children and young people with additional support needs is collected and managed.”

The March 2010 Social Work Inspection Agency report, *Improving Social Work in Scotland*, pointed out where improvement was necessary at strategic level:

*Children with disabilities*

“Quality matters in children’s services” identified three priority areas to improve outcomes for children with disabilities:

- empowerment in decision making and accessing resources
- responsive services and timely support, and
- improving the quality of services.

Overall, services have some work to do to improve performance in these key areas. Parents consistently told us about their concerns in our carer surveys. Families and carers told us that getting enough of the right services was a central factor in improving outcomes for their children. However, the way the services were provided and whether they were easy to access were also important. Parents were more positive about the difference local services were making where they had been consulted and involved in planning services. The SWIA-led multi-agency inspection of services for people with learning disabilities reinforced the view that promoting inclusion and enabling independence was best achieved where services were developed in effective partnership with families, universal service providers and communities.

Disabled people and their carers identified short breaks and breaks from caring as a gap in service provision.

It is the purpose of this report to assess the state of services for disabled children in order to achieve real change and the delivery of better outcomes for children and families.

## **Contexts of Service Delivery**

Services for disabled children and young people can be structured according to a number of different models of disability, particularly the medical and social models. Services are delivered by both medical and social organisations and it is vital that they work effectively together. There is some tension between the perception of a need for a medical diagnosis as a trigger to accessing support, and a service delivery model that reflects the more holistic needs of disabled children and young people. Family expectations of service provision can also be moulded by the nature of the advice and guidance given in the early stages of diagnosis and assessment. The links between poor health, disability and poverty/inequality also provide an important context for the need for and provision of services for disabled children and young people.

*Setting the Scene*, the fSDC baseline survey, establishes a range of contexts, beyond those of definitions and statistics, which might be seen as a starting point on which to build. It is designed as an initial consideration of services and support. There will be an opportunity for those working with disabled children and young people to help identify new or missing data, and examples of best practice, on a regular basis as *Setting the Scene* develops.

Many of the services used by disabled children and young people are provided by local government in one form or another. The relationship between Scottish Government and local authorities takes place in the context of partnership and local flexibility (although there are some areas, such as the provision of Additional Support for Learning, Equality and Disability where there are statutory obligations on local authorities). Current and anticipated financial pressures in the context of reductions in local authority budgets are likely to be a significant factor in future. There are also a number of current activities shaping the context of service delivery for families with disabled children.

Disabled children are more likely to need to receive services from more than one agency. This brings with it complexity which can be mitigated if agencies work together as a single system with designated personnel and professionals taking the responsibility for creating the road map and negotiating it on behalf of families.

Health Boards also play an important role in the partnership. Health board personnel will often act as the lead agency for disabled children in the very early months and years, and health personnel will be Named Persons in the context of GIRFEC, meaning that difficulties are more likely to be identified early and help provided with minimum bureaucracy. Health personnel are also often likely to be Lead Professional for children with complex health needs.

The Self-directed Support Strategy and proposed Bill provides a key opportunity to introduce approaches that put the option of control and funding into the hands of families and young people. Whilst direct payments have been available to disabled children since 2001, uptake has been low, as highlighted and explored in *Improving Social Work in Scotland*:

Direct payments are just one option for implementing personalised approaches and they should be considered and offered during the assessment process ... Nationally, the take up of direct payments has been slow. We made a number of recommendations about the need to support better uptake of direct payments together with improved staff training ... The future of direct payments in Scotland will depend on the willingness of councils to take a more proactive approach to promoting direct payments as an option. People who received direct payments were positive about being able to control their own support. However, the administration of direct payments did not always work well and there were some examples of social work services being unnecessarily involved in controlling the way people used their direct payments.

The Self-directed Support Strategy, launched in November 2010, sets out a 10 year framework for significant change in the delivery of support for both children and adults. The strategy recognises that specific activity will be needed to integrate self-directed support and the GIRFEC agenda, and this will feature in the Action Plan currently being developed by the National Implementation Group. Greater understanding of the nature of current demand and uptake of this approach as it applies to services for disabled children and young people will emerge in the communications strategy to promote this activity, in the current work to consult on an SDS Bill, and will also form part of the work of this review going forward into 2011 and beyond.

The Carers and Young Carers Strategy, *Caring Together and Getting it Right for Young Carers*, published in July 2010 by the Scottish Government and COSLA, is clear about the importance of a whole range of supports to help Scotland's estimated 657,000 carers, including those who care for a disabled child. *Caring Together* sets out over 60 Action Points to help improve support to carers over the next five years. The focus is on improved identification of carers, better assessment, information and advice, health and wellbeing, carer support, participation and partnership.

One of the supports is flexible, personalised short breaks leading to better outcomes for carers. The strategy sets out a range of actions in support of the further development and sustainability of short breaks. This recognises that while progress has been made over the last few years, more needs to be done. The provision of short breaks is high on the list of carers' priorities.

The Scottish Government has made available £5 million over five years (2010-2015) to support the further development of short breaks. This has been awarded to the National Carers Organisations (NCOs) who have developed a scheme, inviting the Third Sector or voluntary-sector led partnerships to apply for funding for short breaks. This Short Breaks Fund will particularly welcome proposals that seek to secure short break provision for disabled children and young people and their families. Securing short breaks for disabled children as they become young adults is also important, as often the period of transition can be neglected. In addition, a further, dedicated £2 million is being made available in 2011-12 for short breaks for severely disabled children.

The March 2010 report *Child Protection and the needs and rights of disabled children and young people* presents evidence that disabled children are 3.4 times more likely to be abused than non-disabled children, and expresses the concern that until recently, Scotland did not address this increased vulnerability in its safeguarding policies. The SWIA report *Improving Social Work in Scotland* noted that:

Children with disabilities had some of the poorest quality assessments and only one quarter of their case files contained a chronology. Given the evidence from many studies that disabled children are significantly more vulnerable to abuse, this is an area for improvement.

Included in the report's observations are that "seeking the views of the young person and their parents and carers and encouraging their participation", together with effective multi-disciplinary working involving social work services, education, health, police and the third sector all contributed to managing risk.

The National Child Protection Guidance – published in December 2010 – does, however, take account of disabled children. Part 4 contains a section devoted to disabled children, providing a good summary of their particular risks and vulnerabilities and signposts to useful materials and resources. In addition, the 'generic' guidance elsewhere in the document highlights the implications for disabled children, for example in stressing the importance of taking account of children's communication support needs.

The contexts in which services to disabled children are developed and delivered are multiple and complex. Acknowledging and addressing this complexity is key to achieving real change.

### **Recognising and managing complexity**

Managing and meeting the needs of disabled children and young people often means managing considerable complexity, both for professionals and families. There are

many facets to this complexity. Statistics tell a story, and can help gauge the scale of an issue, but the interaction between disabled children and young people and their families with the culture and systems of support is perhaps more telling.

Disabled children and young people are by no means a homogeneous group and do not have a uniform set of needs. They live their lives in the context of a very wide and changing range of needs – from single disabilities to multiple, some more visible than others, as well as conditions that will have very varied impacts on aspects of children's lives. These may include behavioural impacts as well as life-limiting impacts on physical and mental health.

Disabled children and young people, their families and carers, are inevitably brought into contact with a wide range of service providers and many people within the organisations assessing and delivering services. At organisational level, this may involve social work, education authorities and schools, the health sector and other local authority services. It is also likely that families will have significant contact with the voluntary sector, either as the direct provider of services or as a key source of advice, guidance, advocacy and information. Contact a Family's *Directory 2010: the essential guide to medical conditions, disabilities and support*, for instance, contains patient-friendly information for children and adults with disabilities, serious health conditions and rare disorders.

Specialisms within these areas provide a further level of complexity. For example, in the case of physical disability occupational therapists deal variously and separately with assessment for wheelchair provision, walking aids, home adaptations, manual handling needs and so on. Physiotherapists may have similarly distinct functions. There will be occupational therapists who work for the social work department, and those who work for the health board; in some areas, it may be that all occupational therapists are formally based as part of services for adult disabled people, and therefore may not have sufficient focus on children and young people. This also applies to speech and language therapists, where there is a sensory and/or communication impairment, child psychologists and mental health professionals. For some, there are also the professionals involved in specific medical conditions.

It is quite possible for a disabled child or young person and their family to have up to ten separate consultants handling a variety of conditions, with perhaps 24 to 30 different contact points dealing with different aspects of care, schooling and support. This complexity is clearly challenging in and of itself, even outside the impact it is likely to have on the successful delivery of outcomes. It is frequently the family that has to attempt to manage that complexity to try and achieve the effective, consistent and coordinated support to meet need, underlining again the need for (and importance of) the lead professional role under GIRFEC.

Disabled children and young people and their families will often require financial support through the benefits system, most notably Disability Living Allowance, Carers Allowance, Housing Benefit and on through a range of additional benefits. The policy and administration of benefits is reserved, though Scottish Government has sought to ensure benefits policy takes account of specific policies designed to support disabled children and young people in Scotland. These involve further (and

frequently duplicated) assessment and represent a further series of complexities for a family to manage.

The interplay between UK disability legislation (for example the UK Equality Act) and legislation on disability in devolved areas such as education (for example, the provisions in the Additional Support for Learning Act on schools accessibility) can add further complexity for families seeking an understanding of the system. This holds true as well for officials at both local and national level seeking to maximise appropriate support for families and to minimise anomalies.

Some of the guidance available to professionals can be complex and vary. This can be as a result of the perceived requirements for each authority or body to produce its own version of guidance, or guidance that is focused on its particular circumstances, even where there is considerable overlap in core principles. As a consequence restrictions are placed on flexibility in the provision of services because of issues such as incompatibility of equipment or over-strict interpretation and application of health and safety legislation, as recorded in one young person's experience:

*I soil myself at school. I tell my teacher, she tells the office. They phone my Mummy. My Mummy drives 15 mins to school and changes me then I go back to class. My school is sympathetic but say they are not allowed to change me when I soil myself.*

Guidance on moving and handling also provides a significant example. There are currently issues around the size and scope of this guidance together with its consistency and the degree of unnecessary duplication across sectoral and professional boundaries. The seemingly perverse effect of restrictions designed to promote health is that the balance between risk and the rights of young people can limit interventions designed to improve the well-being of disabled children. For instance, where schools adopt an approach to risk assessment that is tantamount to risk elimination, rather than appropriate risk management, there are examples of disabled pupils being excluded from school trips or other activities, or indeed trips being cancelled altogether rather than the school working to provide support for pupils with additional needs.

Such an approach can achieve the opposite effect to that intended by the legislation: rather than limiting risk, it risks damaging disabled pupils' independence, resilience and quality of life, as well as increasing social isolation. Outdoor learning for instance can be very liberating for disabled children and young people. Scottish Government guidance makes it clear that schools and authorities should plan to ensure an inclusive approach.

These and other issues are currently being examined in work to develop new guidance on manual handling being undertaken by Scottish Government and Scotland's Commissioner for Children and Young People.

A range of other issues, such as rural remoteness, cross-boundary and inter-agency cooperation (or its absence), ethnicity and sexuality can add further layers of complexity that families and services have to manage. One additional challenge is funding complexity for organisations, both statutory and voluntary, leading to disagreement over budgetary responsibility, even where it is accepted that a service is

needed. Disagreements between different authorities are mostly irrelevant to families' needs, families frequently voicing the belief that they are not concerned with where support comes from, but can impact severely on families as they await potentially remote and challenging decisions. Authorities such as Highland have been able to overcome some of these issues by pooling budgets through their children's committee.

### **The experience of families, disabled children and young people and communities**

While the views of children and young people and their parents are not necessarily identical, there are common themes and common experiences which should underpin any assessment of how services are developed and delivered. Families have a clear appetite for genuinely child-centred services which flex around identified need, are timely and adopt the *Getting it right for every child* approach. Young people and children do not want to be defined simply as "service users"; they have aspirations and desires for wider life experiences and opportunities that are not met simply by the provision of stand-alone services designed to meet specific medical, learning or transport needs. Indeed, fSDC's challenge to everyone involved in services for disabled children captures this wish well: disabled children and young people wish to live better lives, rather than being consumers of services. Statutory services need to be better equipped to meet both of these aspirations, and there is strong potential for third sector bodies and suppliers in helping to identify and meet those aspirations in partnership with families, statutory agencies and each other. For example, greater empowerment of volunteers can dilute the sense of young people simply being the recipients of a service. Personal relationships are important, and informal and voluntary settings have the potential to make the most of these.

The experiences of children and families are substantial, and share a number of common themes:

- Research and anecdotal evidence (amassed from substantial discussions with families held by Scottish Government in 2008-2009, blog posts generated by the fSDC Diary Project and so on) tells of an overwhelming experience for families and carers of "fight, battle or struggle", often with little sense of progress. Families use consistent imagery such as 'black holes' or 'falling off cliffs' to describe the worst parts of this process.
- Families talk of regulatory mechanisms that can be intrusive, where they would like to see them as supportive; mechanisms that can provide more by way of challenge than support; mechanisms that, rather than responding to needs in a flexible, co-ordinated way, can seem inflexible and incomprehensible, and sometimes to more effectively perpetuate systems than meet need. Multiple visits from professionals can appear to families to have more to do with process than outcomes for the disabled child or young person.
- Families are the predominant source of care. SWIA found that of all those with caring responsibilities, those caring for disabled children were most critical of the response of services designed to meet their needs.

- Language and professional jargon also presents problems for families. The way professionals communicate can often lead to the exclusion of families, specialists appearing to talk to each other rather than talking with families. Different specialists have varied understandings of terminology which can also be in conflict with each other. Language, of course, also presents a further layer of complexity for families where English is not the main language spoken. A related issue is a sense, in this instance for several different young people, of not being properly listened to:

*It is good when someone takes the time to listen but time is always a problem.*

*Because I can't talk, some people at school just made up what they thought I was saying. A lot of people just ignored me like some of the therapists and nurses.*

*I would like to make REAL friends, be included in things more, be listened to properly. This is difficult for other people as my speech is not good, but it would be good to be able to have proper in-depth conversations.*

- In discussion with Scottish government, many parents were also keen to share insights into well-run, flexible and appropriate services where they encountered them. There was a strong connection to leadership in these examples, and services delivered directly by the voluntary sector – including those of Sense Scotland, Pamis and Contact a Family – were singled out for consistent praise. Parents noted that building on such identified good practice was essential. Parents are also very open in discussing good services, and the impact they can have, as the fSDC Diary Project blogs reveal:

*I am a very organised person and generally pro-active in regards to our family life and activities. I wanted to meet the management and staff before the end of the nursery school term and make sure they put the resources in place to meet Gwen's skin care needs. After contacting the school in April, I got invited to a 'transition meeting' in May, where I was positively surprised by the support I received.*

*I had prepared a thick report called 'Gwen's Family File' which contained all the information they may need (contacts, history, photographs, treatments, etc) followed by a 'School Service Plan' describing some strategies I thought would be useful: treatment, training, classroom set up, communication between us, etc. (I actually 'stole' the templates from the English 'Early Support' pack on Every Child Matters website. I could feel they were taking me seriously from the start thanks to this useful document!)*

*There were 4 people around me at the meeting: Depute Head teacher, school Doctor and 2 staff (facilities and health officers). All four professionals were very nice and understanding. The DHT even made some brilliant suggestions, e.g. moving the P.E. class next to the lunch break so that Gwen can take her time afterwards getting changed, replacing her bandages and re-applying creams without missing the start of the next class. Or introducing a learning topic in the syllabus about a range of conditions including eczema. How*



*wonderful! It was also very clear that they were going to empower Gwen by allowing her to take control of her care as much as possible, communicate effectively with staff, increase her confidence and become more independent.*

*We then agreed a date for a training session that I would deliver. Early June, I was in school with Gwen as my lovely helper to show three staff how to apply the various creams on her, change her bandages and what to look out for. Finally, we agreed on a monitoring meeting in September. So far, I couldn't wish for more support from the school. This has considerably reassured our family and I now know she will be well looked after.*

- There is often an impact on siblings of disabled children. The extent of this will vary considerably depending on the nature of the disability, the ages of the children and the other supports available to the family. In some situations, siblings of disabled children will contribute by carrying out chores around the house, by helping out their parents, or by looking after their brother or sister. This contribution might be no different from that made by many children, where there is no disabled child. It may also benefit them, as it may equip them with skills, confidence and maturity and they may welcome making a contribution in this way. However, in other situations the siblings of disabled children will have different experiences, due to the impact of the disability, because of what they miss out on, or because of the demands that are placed on them. Some, but not all, siblings of disabled children are young carers who support their parents in the caring role. A few siblings will be the primary carer, especially where they are older, in their late teens. One in three children who are young carers care for a sibling.
- Many siblings of disabled children will have less attention from their parents because of the care and support and time and attention that the parents need to give to the disabled child. Parents of disabled children are often under considerable pressure, which can further limit their ability to give attention to other children in the family. Siblings may also enjoy fewer opportunities because of the impact that the disability has on their family. For example, it might mean that access to community and leisure facilities is limited, transport is a problem, or the family has financial difficulties because one or both parents have to give up work to care for the disabled child.
- Siblings of disabled children who are young carers can undertake an appropriate and positive caring role. However, sometimes the caring role is inappropriate or onerous and will impact on their health, safety, well-being or development. More needs to be done by all agencies to recognise and respond to the needs of the siblings of disabled children. The impact of caring on young people and the kinds of support that can address the adverse impact of caring (including in dedicated young carer projects) is set out in detail in the Scottish Government and COSLA's recently published young carer strategy, *Getting It Right For Young Carers*.
- For disabled children and young people, and their families, service variability between local authority and health board areas is a major concern. Families regularly note the disruption caused by a lack of continuity in staff they work

with, or by geographical service variability. Families frequently comment on the fact that a service which is available in one authority or health board is not available in another, or that a service with full financial support is available in one area but a comparable service requires a contribution from the family in a neighbouring area.

- Families also comment on the interaction between a health board that spans more than one local authority area and its partner authorities; this can lead to different approaches to service provision, whether because of policy positions, financing arrangements or arrangements for staff training.
- Housing is also a central quality of life issue for everyone and can be critical to the well-being of disabled children and young people and their families. Some disabled children and their families will spend a vastly higher proportion of their time in the house than the general population. It is the centre of their world and (for some children) the main extent of it. The home can be a refuge or a prison. Its physical characteristics can make the difference between exclusion and inclusion, along with access to transport, school or family and wider support networks, as well as related issues such as fuel poverty. Regulatory minimum requirements are not necessarily always going to meet the specific needs of disabled children and young people, and in each case – following GIRFEC – thought should be given to putting the needs of children at the centre.
- Disabled young people and their families also experience transitions between all stages of their lives as points of tension and anxiety, with varied experiences of eligibility for assistance. The key issue of transition is explored in more detail below.
- The evidence from disabled children and young people suggests that increasingly it takes a crisis in the home, or in some aspect of the family's life, to act as a trigger to action and the release of necessary resources on the part of services, including those provided by social work departments or their equivalent. Responding in crisis situations is stressful for the young person, for the family, and for different services involved. A service response in stressful circumstances is less likely to be well co-ordinated and efficient. Yet for some reason, early intervention that might prevent the stress of crisis (of which there are numerous good examples) is not the commonplace experience it should be. In the words of one young person:

*I want to be treated the same as my brothers, I want to go to a school that teaches me how to read and do maths like normal children but the council don't do this for disabled children, they don't think we matter. If we matter, then why are the disabled children in school 5 hours less than normal children? Parents have been shouting about this for years but it is easier for people to pretend they don't hear. Mum has complained about me being badly treated at the school and the council a whole month later have done nothing, they don't care about disabled children and it makes me feel horrid.*

(Scottish Government published guidance on this issue in circular 4/2002, noting “As a general principle, Scottish Ministers regard it as unacceptable that pupils in special schools and units have a shorter school week than those pupils of the same age attending mainstream schools. They wish education authorities to review their practice in this regard.”)

- Disabled children and young people, and their families, need to be comfortable accessing services, such as school (whether mainstream or special); physical support; personal assistance; financial help; leisure and related services; transport, childcare and so on.
- Disabled children, young people and their parents and carers can benefit from good quality, flexible short breaks or respite provision. Such breaks provide an enjoyable and stimulating opportunity for children. They can also give the carers a chance to recharge batteries. The breaks can also be taken together, for example as a holiday, with additional support if necessary. Sometimes the service is provided in the home for the disabled child, with the carer having time to do something themselves. The value of such time is evident in parents’ comments when blogging their experiences:

*I am a full time carer and mum to Mary and Jenny – she needs 24 hour care, and she gets it! She requires frequent suctioning and because of her inability to swallow she can't protect her airway, so she is always at risk of choking or aspirating, so myself and David take shifts through the night so she always has someone watching her, and I am with her all day as David is at work. We wouldn't change a single thing about our lives, but what would be nice is if we had more help!*

- The Carers and Young Carers Strategy, *Caring Together* and *Getting it Right for Young Carers* published in July 2010 by the Scottish Government and COSLA, is clear about the importance of a whole range of supports to help Scotland’s estimated 657,000 carers, including those who care for their disabled children. One of the supports is flexible, personalised short breaks leading to better outcomes for carers. The strategy sets out actions in support of the further development and sustainability of short breaks. This recognises that while progress has been made over the last few years, more needs to be done. The provision of short breaks is high on the list of carers’ priorities.
- The Scottish Government has made available £5 million over five years (2010-2015) to support the further development of short breaks. This has been awarded to the National Carers Organisations (NCOs) who have developed a scheme, inviting the Third Sector or voluntary-sector led partnerships to apply for funding for short breaks. This Short Breaks Fund will particularly welcome proposals that seek to secure short break provision to disabled children and young people and their families. Subject to Parliamentary approval of the draft budget, £2 million is also being made available in 2011-12 for short breaks for severely disabled children.
- The provision of short breaks is not, of itself, sufficient to help reduce the stresses families and young people experience. Action for Children has

completed an evaluation of provision of short breaks and intensive care for young people with challenging behaviours. The evaluation found that the specific, specialist and targeted provision enabled children develop a range of skills and gave them increased opportunities for participating in community activities, although social inclusion remained limited compared to their non-disabled peers. It found that parents benefit when their support needs are identified and trusted relationships forged, and where the nature of the service is regularly reviewed. Action for Children also noted that no clear pathways exist for the transition to adult services.

Transition – at all stages of a child and young person’s life – is also a consistently challenging aspect raised in almost every instance where families’ views are sought. Transition is explored in more detail in a dedicated section below.

### **What would disabled children and young people like to see?**

When disabled children are engaged on what matters to them, they frequently express a view that what matters is less the specific nature of formal services – though clearly services are important – and more being enabled to live lives similar to those of their non-disabled peers. That is, the ‘better lives’ highlighted as a key goal by fSDC in its call for us to move collectively ‘From good intentions to better lives’.

Work done by York University has summarised these needs very succinctly:

#### Fundamental outcomes

- Physical and emotional well-being
- Communication
- Personal safety

#### Higher level outcomes

- Enjoying and achieving
- Making a positive contribution
- Economic well-being.

The Children in Scotland report *Access all Areas* also provides one set of insights into the range of things that matter to pupils. The views set out below are mirrored in work done by the Highland Children’s Forum, and an East Lothian engagement with parents:

#### *Staff – what pupils like and respect*

- Members of staff who make all pupils feel like they “fit in”
- Members of staff who provide good role models to other pupils, particularly in the way they treat children and young people with additional support needs
- Teachers who listen; encourage; do not shout but exert discipline; take time to explain; respect confidentiality; and who create a ‘safe’ learning environment

- Teachers and additional needs assistants who get the balance right between providing enough but not too much support.

*Resources – What pupils would like to see*

- More additional needs assistants in classes
- Increased one-to-one or small group input for pupils with learning difficulties
- Current input from Learning Support teams and specialist resources continuing
- The effective support provided through Special Exam Arrangements to be continued
- Clear, easy to use system (possibly authority wide) for pupils to request new equipment and also find out what is available
- Equipment that has been requested appearing without delay.

*Thinking out of the box – what pupils want and need*

- Creative solutions that are tailored to each individual, as one size does not fit all
- On-going support for, and further development of initiatives that are working, e.g. peer supports, using outside professionals, linking with colleges etc
- People thinking about the little things as well as the big ones, since these do make a real difference.

*The building – what pupils would like to see*

- All changes to the building and equipment should be put in place before pupils with additional support needs arrive
- Pupils who will be affected should be actively involved in planning adaptations to existing schools
- All pupils should be engaged and involved in the design of their new schools
- Careful, long term planning for the reality that schools will serve more pupils with additional support needs in the future (moving away from reacting on a case by case basis).

It is evident that both children and young people themselves, as well as their parents, hold and express clear views on changes to systems, practice and culture that would transform services, and in turn help to deliver the better lives they seek.

**Transition from early experience, schooling and on to adulthood – the experience of disabled young people**

Transition at all stages, whether from birth to home, home to nursery, primary to secondary, to a new home or residential situation or transition into a new specialist service, is a key issue for children, young people and families. As the ASL Act and supporting code of practice make it clear, it is anticipated that any child or young person with additional support needs should have a transition plan in place. On moving to adulthood, this should be a particular priority, not least to mitigate the confusion that can arise where, for example, variable statutory and non-statutory ages apply for changes to “adult” status: 16 appears to be the cut-off in the health sector

but it can be anything from 16 to 18 to 21 in different authorities and sectors. At this point, there can be significant changes in care personnel, pathways and packages of support, and forward planning makes a positive difference when undertaken in consultation with families. It is a challenge underlined by young people's views:

*It would be good if my teacher knew more about type 1 diabetes this year. Every time I get a new teacher she never knows what do to help me and mum has to do everything again. I don't really like it when everyone knows about my diabetes at school. A teacher shouted at me one day for not getting my test kit on a school trip. My mum wrote a letter to say she wasn't happy about that because she said the school should look after my test kit when I go on a trip. The head teacher told me I wouldn't get into trouble again for my diabetes.*

At points of transition, families' sense of "fight, battle and struggle" can often recommence. This point is amplified in *Improving Social Work in Scotland*:

#### Planning for young people with disabilities and/or complex needs

Here, the most frequently expressed concern was the lack of forward planning in the period leading up to leaving school. We heard many instances where assessments were left to the last minute, where funding was not in place and young people were waiting for long periods before being allocated a worker from adult services. The adoption of a more personalised approach was needed. Lack of planning for the move from childhood to adulthood and independence raises powerful emotions for many parents and carers who described themselves as 'fighting for services' ...

Where transitions were working well, there was good multi-disciplinary working. Increasingly, services were developing local multi-agency forums to screen referrals, plan interventions and anticipate resource requirements. Clackmannanshire Council employed a transitions co-ordinator, based within psychological services who promoted joint working with colleges and early engagement with parents. Transition services for young people with learning disabilities were better developed than for those with physical disability, autism and mental health problems. Some services had developed specialist resources for these groups of young people and where this was the case, families welcomed the improvements. Such improvements were usually underpinned by:

- a shared perception and approach between child and adults services and partners
- sufficient expertise in both child and adult teams and partner agencies
- clear agreement and timescales to avoid crisis driven responses
- accurate transfer of information between services
- income maximisation at an early stage, and
- exploring self-directed care options well in advance of transition.

There are many existing examples of good approaches to managing transitions, such as the Big Plan (which is a form of group person-centred planning bringing together disabled young people and their families to think about what would make a good life

for them in the future). A recent Capability Scotland report on Big Plan work in East Lothian captured a number of families' take on its value:

*The Big Plan has made me feel over the moon. It's inspiring; we just express ourselves and people listen. We are with our friends.*

*The Big Plan has opened my eyes. It has made me see what my daughter is good at, and how she could use that in the future.*

Similarly, Highland Children's Forum produced a report in 2007 – *It's My Journey* – exploring the experiences of young people making the transition to adult services which has helped to positively shape new guidelines and protocols around transition.

The HMIE report into the implementation of the ASL Act noted that overall across Scotland, education and health professionals work together effectively to identify and assess children's needs before they enter pre-school service. There are also examples of evidence about transitions and other experience in a wide range of web-based material. One key set of evidence is laid out in the Diary Project led by For Scotland's Disabled Children.

The range and depth of information and counselling support and advice is not always well presented or co-ordinated, and the potential disjunction for families of having to deal with multiple contacts, change contact details and navigate a stressful change at the same time represents a major life hurdle. Disabled children and young people's experience, as well as that of their families, is that these tracks do not as a rule run smoothly.

The views of disabled children and young people themselves must be taken into account in the provision of services. There is a need to tap in more systematically, and in a more varied range of ways, to the way young people view the routes they take through life and the barriers they have to face or envisage. This review has therefore started to develop thinking around a model that with additional input from young people could provide a useful vehicle for stimulating the necessary ongoing dialogue for improvement. As part of this review's work, young disabled people have been asked for their views on the model, and it is clear that its validity needs to be checked further, and disabled young people need to be involved in the further development of a credible and useful model.

Young people said that any model for describing the process of transitions at all stages needed to:

- Look at young people in terms of the wider world
- Be wider than just about school and education
- Show how “everyone is going through the same thing but in different ways”
- Focus on friends
- Allow for aspirations – “you might want to travel the world when you leave school”
- Include your family
- Involve “working together as a team”.

One of the ways to overcome the transition barrier that face many young people is to access the services and support of a Local Area Co-ordinator. Local Area Co-ordination (LAC) was introduced in Scotland in 2000 following the national review of services for people with learning disabilities (*The same as you?*). The role of the LAC is seen as an innovative way to support individuals with learning disabilities and their families, helping them to access information to help make informed decisions about what support, services and resources that they want, and promoting inclusion through making links with the community.

The Scottish Government is committed to promoting independent living for disabled people. The definition of independent living we use is disabled people having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life:

- **Participating in society means** being able to access education, work opportunities and justice; and being able to contribute to Scotland's democratic processes on equal terms
- **Living an ordinary life means**, for example, having equal opportunities for housing, transport, shopping and leisure.

A programme of work is in place across the Scottish Government and the wider public sector to promote independent living.

### **Identifying key needs**

In the contexts outlined above – statistics, definitions, complexity and significant individual issues such as transitions – it is vital to identify the key needs of families. Key needs are less about the detail of provision of equipment and services (though the issue of equipment portability between local authority areas can be challenging) or about financing, although both of these are of course important. Key needs are more about basing services on a foundation of equality and empowering disabled children and young people and their families through the availability of high quality, coherent information, as well as making concerted efforts to minimise the effects of service fragmentation.

Good practice needs to be identified and promoted to a greater extent than currently happens. Practice will increasingly need to respond in innovative and creative ways in order to provide a level of service that meets needs as effectively and efficiently as possible in the light of budget challenges both now and in the future. The core components of a GIRFEC approach, with a focus on young people's and families' needs regardless of service processes, must be more clearly embedded in providers' strategic and business planning and in their practice. Where the GIRFEC approach has been put in place, the needs of children with complex difficulties being managed through a single planning process that results in a single Child's Plan has been shown to not only improve how services are delivered but critically the experience of



children and their families. Any plan should set out what is to be achieved, the actions required (and by whom) to achieve that change, and must fully involve the child and the family in finding and implementing solutions as partners to the plan. Any such plan should be co-ordinated by a Lead Professional.

Partnership is critical. *Improving Social Work in Scotland* underlines the fact that practice is improving, but that much still needs to be done:

#### Partnership working

Social work services generally worked well with partners, providing an important contribution at both strategic and operational levels. Community planning, and the advent of single outcome agreements had provided particular impetus at strategic level. The commitment made by chief officers from councils, the police and NHS to child protection strategic partnerships was evident in many areas, as was the contribution of directors of social work/chief social work officers. The GIRFEC agenda, as well as the Scottish Government's promotion of corporate parenting, had added fresh impetus at both strategic and operational levels. The response of councils was variable in both these areas. We made recommendations where we felt partnership working needed to improve. At the follow-up stage of our performance inspections, services had often established new processes and agreements. However, in other instances, progress had at times been slow, and the existence of a protocol was no guarantee of implementation or compliance.

This review has highlighted, as have previous reviews of children's services and the GIRFEC evaluation study in 2009, the need to strengthen and enable effective multi-agency collaboration. While the format of such collaboration is not something that we should look to prescribe, as relationships in different areas will be suited to different locally-appropriate approaches, examples exist of joint management arrangements between local authorities and health service provision; of co-location of services; informal committees bringing front-line staff together; empowerment of mid-level staff; and the provision of appropriate technologies, such as the use of video conferencing or shared appointment systems, to make the processes of meeting young people's and families' needs easier for them and more efficient for the authorities concerned.

More effective use of specialised teams – such as an authority-wide disability service, drawing on partners – can also allow authorities to:

- Have better knowledge of the client base
- Involve families more and more effectively and understand their social care, schooling, housing/adaptation and short breaks needs
- Improve service continuity
- Improve links between partner services and other services
- Play a developmental role in service provision (for example, increasing volunteer involvement in holiday schemes)
- Share equipment and improve provision of equipment and appropriate technologies.

Staged interventions, designed to meet the identified needs of disabled children and young people, can be a useful model, and this model might be the first port of call as soon as a disability is diagnosed. The November 2010 review by HMIE of the implementation of the ASL Act found that:

Most authorities have built effectively on established multi-agency working to provide improved assessment and advice on the most appropriate level and types of support that a child or young person requires.

Staged intervention, in conjunction with the GIRFEC practice model, is helping to ensure that children's needs are being addressed more holistically. Importantly, it is also helping to secure a better say for children and parents in the decision-making processes.

Some authorities have made use of Codes of Practice or Needs-led assessment models that should be further examined in order to determine their effectiveness. Cost-benefit analysis of early use of such intervention models would facilitate long term comparison between different approaches.

Different families will welcome different forms of support. Some may not necessarily be in the best position to press for their own needs to be met. In the face of regulatory complexity and organisational interests, there is a case for enabling greater use of named individuals (or key workers) who are charged with collating the needs and working with the relevant organisations to better co-ordinate the service provision. This can include timetabling and co-ordinating appointments, collating information in a readily shareable form, or arranging for the provision of necessary equipment. This would take a considerable burden from families, and may well be an investment that would reduce duplication and financial pressures from the public sector as a whole. The role is also compatible with the roles of Named Person and Lead Professional developed as a key part of the GIRFEC approach.

At the same time, one of the striking elements of evidence from disabled children and young people and their families is the sense of being disempowered, of being at the receiving end of decisions made by seemingly distant authorities and health boards about the nature, timing and availability of services such as care and short breaks. There is a case for more positive use of direct payments and self-directed support to support those families who wish to make their own decisions about the needs that have to be met and how to meet them. Increased control of one's own life, supported by appropriate information and guidance, can increase the sense of self worth and self reliance for those families who would welcome managing such an option. Implementation of the National Self-directed Support Strategy will consider the range of information and support that is needed to empower individuals and families to make these informed choices. The Self-directed Support Bill will underpin this activity, aiming to bring self-directed support into the mainstream of social care delivery.

### **Identifying key system supports, as well as the failures, gaps and inconsistencies**

Systems, culture and practice are, for many disabled children and young people and their families, improving. These remain a long way from where they need to be if national priorities are to be reached in a manner that realises the *Getting it Right Well-being* Indicators and delivers demonstrably better outcomes for children. There is good practice, but it is often hard won, and can be too rare. In developing this interim report, the review group has encountered many specific instances of system, practice and culture challenges in which improvements need to be made if we are to significantly improve outcomes for children.

These include:

- Inadequate attention being paid to the opinions and experiences of disabled children and young people.
- Children’s Services Plans provide an excellent mechanism for budgeting and managing in the light of changing demands, changing technologies and changing contexts, but need to be kept up to date on a regular basis, and to identify the priority attached to services for disabled children and young people and their families.
- Universal services, such as education and leisure, need to be seen as truly universal and operated from a basis of equal access for all. The costs of inclusion of disabled children and young people should be an integrated element of planning for the well-being of all children and young people.
- There is a need for stronger capacity building amongst a wider range of bodies in responding to the needs of disabled children and young people. East Lothian parents have expressed this concern simply: “The inclusion of children with additional support needs within mainstream activities is still an issue. Parents gave examples of where their child/relative had been treated differently from children who do not have additional support needs. Parents felt that more needs to be done to make activities more inclusive – for example, afterschool clubs, active sports, and community groups. Staff may need more training on making their service inclusive.”
- Frustration is caused by multiple routes of access to providers of advice and support, and there is the potential for greater recognition of the role of the third sector in providing services supplementary to NHS services.
- The process of assessment of needs and the provision of services by multiple providers can involve wasteful duplication and confusion. The adoption of Transferable “passport” assessments (such as Disability Living Allowance) would reduce this and generate efficiencies.
- There is a need to improve sharing of information to improve planning and budgeting for services. From the user perspective, information on services can also be partial, confusing and difficult to obtain in accessible form.
- Looked after disabled children and those in hospital have educational and social needs that can often be overlooked.

- Medical support in schools is a critical area of support to enable some children and young people to take advantage of all the curriculum has to offer them. There is a significant body of advice on medical support which can be interpreted in a restrictive way, and provision is patchy.
- Agreeing clear guidance in appropriate areas will be important if services are to share aspects of service provision more effectively.
- Understanding of child protection issues as they affect disabled children and young people needs to be improved.
- In terms of the particular needs of young people in transition, More Choices More Chances has seen the creation of 32 local multi-agency partnerships (local-authority led) whose aim has been to increase the number of young people in positive and sustained destinations. This has seen improved partnership working, better integration of services, and earlier identification of vulnerable children and young people which enables appropriate support to be put in place.
- The implementation of the Education (Additional Support for Learning) (Scotland) Act 2004 which was amended and strengthened by the 2009 Act of the same name is playing an important part in helping to ensure that children and young people receive the help they need to be successful learners. Practitioners across services for children are more aware of many of the issues that can hinder learning and their individual and collective responsibilities for identifying and addressing them. Authorities have established staged intervention processes that are promoting and strengthening multi-agency working and better targeting of resources. Staged intervention, in conjunction with the GIRFEC practice model, is helping to ensure that children's needs are being addressed more holistically. Importantly, it is also helping to secure a better say for children and parents in the decision-making processes.
- 16+ Learning Choices, an integral part of Curriculum for Excellence, provides for an offer of appropriate and personalised post-16 learning well in advance of the school leaving date. This offer will encompass relevant supports to help young people make effective learning choices. Effective delivery requires building on wider activity to support young people needing more choices and chances, embracing the principles and practice around *Getting it right for every child* and the Additional Support for Learning Act.
- In 2008, the Scottish Government and the Scottish Funding Council (SFC) commissioned BRITE (Beattie Resources for Inclusiveness in Technology and Education) to look at provision in Scotland's colleges for students with profound and complex needs. The report found that there was a greater range of provision in a larger number of colleges than there had been 10 years earlier. It also confirmed that programmes had by and large been developed in response to growing numbers of applications. All of this is borne out by SFC statistics which show that the number of enrolments from students requiring

additional support on special programmes rose between 1998 and 2008 from under 20,000 to just over 35,000.

- The report went on to suggest that more resources needed to be committed to developing staff who work with students with profound and complex needs and that support and therapy services should be brought together in ‘centres of excellence’. The report recognised that, unlike in England, there was no college in Scotland where all these services were co-located and reported a mix of views around the need for such a facility here.

There are also areas where those working with disabled children, from a wide range of sectors – including, but not exclusively, social work, health and education – would benefit from well planned and co-ordinated skills development that will help build a deeper understanding of the issues where impacts are significantly different than for non-disabled children. These needs go beyond the development of specific skills within specialisms, and might be summarised as primarily to do with:

- (a) Improving the standard of communications with disabled children and young people and their families
- (b) Significantly improving the collaborative working relationship between different sectors.

The identification of these development needs at this point is timely, coinciding with the establishment of a Scottish Government working group to articulate common elements to professional development across the broad children’s workforce. This report will provide useful evidence for the working group, and will provide a common foundation from which partners can engage in the planned consultation period.

### **Interesting practice – some examples**

It is important to maintain and promote awareness of good practice where it exists, especially in the face of the numerous challenges thrown up by the report. The “Pathways to Care” model produced by the national managed clinical care network provides a useful example of how disabled children’s route through the system can be described as a more co-ordinated journey, with guidance on each step helpfully signposted in an on-line resource.

The NHS National Delivery Plan for Specialist Children’s Services reviewed the guidance covering financial assistance with structural adaptations for homeowners who are disabled or have disabled children and found it broadly appropriate; it remains for authorities and health boards to agree aspects of provision in line with the guidance.

The National Delivery Plan for specialist children’s services in the medical sphere (£32m over three years, with recurring funding commitments) contributes to those with severe conditions; one element of the funding is for the establishment of a managed clinical network for children with exceptional healthcare needs (CEN) based in South East Scotland and Tayside.

Guidance on supporting all learners in learning has been published by Learning and Teaching Scotland, identifying how, in the context of Curriculum for Excellence, both universal and targeted support should emphasise how young people can be enabled to gain the maximum possible advantage from their learning.

There is also more targeted advice on getting learning provision right, for example through guidance issued on Autism/Dyslexia relating to identification and provision of needs. The next phase of work by partners involved in the development of this review will include the collation of a substantial set of good practice examples and case studies.

## **Future actions**

The agenda for improvement laid out in this report of the national review of services for disabled children is very challenging and broad. In view of this significant challenge, it is important to note that progress is already being made within the children's disability agenda, and much work that will generate positive outcomes for children is already in hand or planned.

Against this background, the report now sets out a plan for action – underpinned by key principles, to which each of the three lead partners in the review subscribes – with timings, indications of which relevant partner will lead the action, and an initial assessment of those aspects of children's well-being flagged as SHANARRI indicators under the GIRFEC approach each action supports.

## **Actions and Principles Flowing from the Review**

The three lead partners in the national review of services for disabled children – Scottish Government, COSLA and For Scotland's Disabled Children – and the review group charged with developing this report believe that to deliver better outcomes for disabled children, young people and their families we should work to the following principles:

1. In line with the *Getting it right for every child* approach, we will strive to create a single system for the delivery of flexible, timely and appropriate services focusing on the needs of the child.
2. In line with *Getting it right*, we will see each child first as a child, and second as disabled, acknowledging that every child has views and preferences as well as a way of expressing them, and that disabled children have the same range of interests and aspirations as their peers.
3. Service development, assessment and delivery should be transparent, fair and equitable.
4. Within acknowledged constraints, we will endeavour to empower children and families through the availability of greater choice and control.
5. We will strive to achieve the right balance between risk assessment and the promotion of children and young people's autonomy, resilience and ability to grow.

6. We will aspire to deliver outcomes for children and young people across Scotland which consistently meet their needs and rights.
7. We will fully engage with children and young people in the implementation of actions flowing from this review, and in the range of activity involved in the ongoing development and delivery of services.

## Plan for Action

ACTION	LEAD / SUPPORT PARTNER	TIMESCALE	ASPECT OF WELL-BEING SUPPORTED (SHANARRI)
We will invest an additional, dedicated £2m in short breaks for families with severely disabled children. This builds on the existing £5m for short breaks between 2010 and 2015, where one priority for the use of this resource, after an initial assessment stage, is disabled children and their families	Scottish Government  National Carers Organisations, additional voluntary sector partners	Financial year 2011-2012	Active, Included – short breaks increase family cohesion, inclusion of children and young people in broader networks and parental support
We will pilot the fSDC Charter for Scotland's Disabled Children in several local authority and related health board areas (text at Annex C)	Individual LAs, health boards, fSDC Liaison Project	2011-12	Respected, Included – the charter provides for significant degrees of engagement by children, young people and families in development and delivery of the services they need
Working with partners, Scottish Government will develop and publish a <i>Getting it right for every child</i> practice briefing setting out how the GIRFEC approach applies to disabled children	Scottish Government  Relevant partners	2011-12	All aspects – <i>Getting it right</i> aims to enable children and young people to fulfil their potential across the whole spectrum of well-being indicators
We will publish new national guidance on manual handling for disabled children	Scottish Government, Scotland's Commissioner for Children and Young People	2011	Respected, Safe, Active, Included – appropriate manual handling with an emphasis on dignity, respect and inclusion can have a transformative effect on young people's well-being
We will develop and disseminate a robust	fSDC Liaison Project	2011-2012	All aspects – Safe, Healthy, Active,



<b>ACTION</b>	<b>LEAD / SUPPORT PARTNER</b>	<b>TIMESCALE</b>	<b>ASPECT OF WELL-BEING SUPPORTED (SHANARRI)</b>
evidence base of good practice across a range of key areas, such as transition, which promotes the SHANARRI outcomes for disabled children and young people and builds on evidence developed in <i>Setting the Scene</i>	Relevant partners		Nurtured, Achieving, Respected, Responsible and Included
In line with the <i>Getting it right</i> approach, we will develop a workstream to explore the consistency of deployment and training of staff across disciplines relevant to services for disabled children	Review group  Relevant partners	2011-12	All aspects – this broad workstream will influence aspects of well-being across the SHANARRI spectrum
Within a <i>Getting it right</i> context, we will explore the potential of integrated children’s services inspection regimes to focus on disabled children that drills down to cover services that make provision for them as individuals	Scottish Government  Relevant inspection bodies	Ongoing	All aspects – where the GIRFEC approach is implemented, inspection of aspects of well-being across the spectrum will be necessary
We will seek to reinforce the importance of regularly reviewed children’s services plans to ensuring improved outcomes for disabled children	COSLA, individual authorities	Ongoing	Respected, Included – Raising the strategic profile of disabled children is important, and regular review of this key strategic tool will help ensure outcomes for children improve
We will identify and promote ways to make the child protection system more accessible to disabled	Individual authorities  Health boards, voluntary	Ongoing	Safe, Healthy, Nurtured – striving to appropriately protect disabled children at all levels, while taking

<b>ACTION</b>	<b>LEAD / SUPPORT PARTNER</b>	<b>TIMESCALE</b>	<b>ASPECT OF WELL-BEING SUPPORTED (SHANARRI)</b>
children and sensitive to their needs, promote closer working between children's disability and child protection/social work teams in relation to safeguarding and seek to ensure all local CP guidance takes account of disabled children	sector and justice partners		account of their views and needs, is integral to ensuring children and young people are safe and nurtured
Scottish Government will ensure the national Child Poverty Strategy takes account of children's disability issues raised by this review	Scottish Government	2011	Nurtured, Respected – resolving poverty for families with disabled children is a key challenge, and we must embed financial issues for disabled children in this key strategic context
Scottish Government will strengthen the children's disability aspects of the self-directed support agenda	Scottish Government	2011	Included, Respected, Active – empowering young people through greater choice and control over their support is central to the aims of this review
We will review learning provision for children and young people with complex additional support needs through the Doran Review	Scottish Government	2011-2012	All aspects – The Doran Review will aim to ensure every child in Scotland with complex additional support needs receives the individual support they need to access learning and realise their potential. Every child has the right to feel safe, healthy, active, nurtured, achieving, respected, responsible and included
We will develop an ongoing communications strategy that actively engages disabled children, young people and their families	Review group	2011	Included – as the review report has included initial consultations with young people, we are committed to fully involving young people in the ongoing work of

<b>ACTION</b>	<b>LEAD / SUPPORT PARTNER</b>	<b>TIMESCALE</b>	<b>ASPECT OF WELL-BEING SUPPORTED (SHANARRI)</b>
			implementation (and to putting principle 2 into practice within this process)
We will continue to take forward work to ensure disabled children and their families are able to benefit from progress we are making towards independent living	Scottish Government	Ongoing	Included, Active, Achieving – this action recognises the value in developing better support in points of transition throughout children’s lives, and beyond into adulthood
In line with <i>Getting it right</i> , we will ensure disabled children’s needs remain at the centre of housing support	Scottish Government	Ongoing	Safe, Respected – in addition to work to increase dignity and respect for children and young people through our action on manual handling (which itself has housing aspects), and following the GIRFEC emphasis on putting children’s needs at the centre, it is important to work to further embed the needs of disabled children in work around housing support

## **ANNEX A – Membership of the Review Group**

The full membership of the group invited by Scottish Government, COSLA and the fSDC Liaison Project to conduct this review is as follows:

- Harriet Dempster (Chair)
  
- Margaret Allison, Scottish Government
- Ellenor Anwyl, Contact a Family
- Mark Ballard, Barnardos
- Paul Begley, South Lanarkshire Council
- Mark Bevan, Capability Scotland
- Allan Cowieson, North Ayrshire Council
- Stephanie Fezas-Vital, Scottish Government
- Sharon Glen, Scottish Government
- Shelly Gray, LTCAS
- Pat Jackson, NHS Lothian
- Sandra McFadyen, Quarriers
- Monica McTurk, NHS Dumfries and Galloway
- Joanne Milligan, Fife Gingerbread
- Robert Nicol, COSLA
- Moira Oliphant, Scottish Government
- David Purdie, Scottish Government
- Willie Rutherglen, Parent
- Kirsten Stalker, Strathclyde University/fSDC Liaison Project
- Rachel Sunderland, Scottish Government
- Robert Swift, East Lothian Council, Parent
- David Thompson, Scottish Government
- Nick Watson, Glasgow University
- Barbara Wright, Action for Children
  
- Colin Brown, Scottish Government (Secretariat)
- Rod Burns, Scottish Government (Secretariat)

## ANNEX B – References and Resources

- *2008 Survey of Provision in Scotland's Colleges for Learners with Profound and Complex Needs*, BRITE initiative, 2008:  
[http://www.sfc.ac.uk/nmsruntime/saveasdialog.aspx?filename=survey\\_of\\_provision.pdf](http://www.sfc.ac.uk/nmsruntime/saveasdialog.aspx?filename=survey_of_provision.pdf)
- *Access All Areas: what children and young people think about accessibility, inclusion and additional support at school*, Children in Scotland, June 2007:  
[http://www.childreninscotland.org.uk/html/par\\_acc.htm](http://www.childreninscotland.org.uk/html/par_acc.htm)
- *Big Plan*, Capability Scotland, January 2010 – website: <http://www.capability-scotland.org.uk/thebigplan.aspx>
- *Caring Together: The Carers Strategy for Scotland 2010 – 2015*, Scottish Government, May 2010:  
<http://www.scotland.gov.uk/Publications/2010/07/23153304/0>
- *Changing Professional Practice and Culture to Get it Right for Every Child: an evaluation report of the development and early implementation phases of Getting it right for every child in Highland, 2006-2009*, Scottish Government, November 2009:  
<http://www.scotland.gov.uk/Publications/2009/11/20094407/0>
- *Child protection and the needs and rights of disabled children and young people: A scoping study*, Faculty of Education, University of Strathclyde, March 2010: <http://strathprints.strath.ac.uk/27036/>
- *Circular 4/2002 Length of School Week: Pupils in Special Schools and Units*, Scottish Executive, April 2002: <http://www.edlaw.org.uk/wp-content/uploads/pdfs/guidance/week.pdf>
- *Diary Project*, for Scotland's Disabled Children, ongoing web publication: <http://www.fsdc.org.uk/blogs>
- *Education (Additional Support for Learning) (Scotland) Act 2009*, Scottish Parliament, 2009:  
[http://www.oqps.gov.uk/legislation/acts/acts2009/pdf/asp\\_20090007\\_en.pdf](http://www.oqps.gov.uk/legislation/acts/acts2009/pdf/asp_20090007_en.pdf)
- *Equality Act 2010*, UK Parliament, 2010:  
<http://www.legislation.gov.uk/ukpga/2010/15/section/6>

- *Factsheet 15 – Education and disability rights*, Enquire, the Scottish advice service for additional support for learning, November 2010:  
<http://enquire.org.uk/publications/factsheets/education-and-disability-rights>
- *Family Directory 2010: The Essential Guide to Medical Conditions, Disabilities and Support*, Contact a Family, 2010:  
<http://www.cafamily.org.uk/medicalinformation/subscribe.html>
- *Improving Social Work in Scotland*, Social Work Inspection Agency, March 2010: <http://www.scotland.gov.uk/Publications/2010/03/24113359/0>
- *Implementing the Housing (Scotland) Act 2006, Parts 1 and 2: Statutory Guidance for Local Authorities: Volume 6 Work to Meet the Needs of Disabled People*, Scottish Government, March 2009:  
<http://www.scotland.gov.uk/Publications/2009/03/25154356/0>
- “*It is not about money or resources. It is about empathy and intuition*”, Highland Children’s Forum, 2010:  
<http://www.highlandchildrensforum.org/userfiles/file/GIRFEC%20family%20views%20report%20sm.pdf>
- *It’s My Journey*, Highland Children’s Forum, 2007:  
<http://www.highlandchildrensforum.org/library.asp>
- *National Guidance for Child Protection in Scotland 2010*, Scottish Government, December 2010:  
<http://www.scotland.gov.uk/Publications/2010/12/09134441/0>
- *Outcomes for Disabled Children*, Social Policy Research Unit, University of York, September 2007:  
<http://www.york.ac.uk/inst/spru/pubs/rworks/aug2007-02.pdf>
- *Pathways for Care*, NHS Scotland – National Managed Clinic Network, December 2010 (updated): <http://www.cen.scot.nhs.uk/pathways-care.html>
- *Pupils in Scotland, 2009*, Scottish Government, February 2010:  
<http://www.scotland.gov.uk/Publications/2009/11/05112711/120>
- *Review of the Additional Support for Learning Act: Adding Benefits for Learners*, Her Majesty’s Inspectorate of Education, November 2010:  
<http://www.hmie.gov.uk/documents/publication/raslaabl.pdf>
- *Scottish Health Survey 2009*, Scottish Government, September 2010:  
<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/scottish-health-survey/Publications>
- *Scottish Household Survey 2009*, Scottish Government, December 2010:  
<http://www.scotland.gov.uk/Topics/Statistics/16002>

- *Self-Directed Support: A National Strategy for Scotland*, Scottish Government, February 2010:  
<http://www.scotland.gov.uk/Publications/2010/02/05133942/0>
- *Setting the Scene*, for Scotland's Disabled Children, November 2010:  
[http://www.fsd.org.uk/assets/files/fSDC\\_Summary\\_report\\_2010.pdf](http://www.fsd.org.uk/assets/files/fSDC_Summary_report_2010.pdf)
- *Social and economic value of short breaks*, Action for Children, December 2009:  
<http://www.actionforchildren.org.uk/uploads/media/36/9163.pdf>
- *Support Needs System*, NHS Scotland ISD, ongoing web publication:  
<http://www.isdscotland.org/isd/3397.html>
- *Supporting all learners*, Learning and Teaching Scotland, 2010, ongoing web publication:  
<http://www.ltscotland.org.uk/supportinglearners/whatissupport/thenationalframework.asp>
- *"The same as you"*, Scottish Executive, May 2000:  
<http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>
- *What North Ayrshire's Pupils and Parents told us – Additional support for learning across North Ayrshire*, Children in Scotland, 2008:  
<http://www.childreninscotland.org.uk/docs/pubs/NorthAyrshireASLsummaryreport08.pdf>

## **ANNEX C – Text of the FSDC Charter for Scotland’s Disabled Children**

In our local authority/health board we are committed to turning good intentions into better lives by meeting all our statutory obligations towards disabled children and young people, and their families.

We will also ensure that by [ ] (insert date here)

- We put the disabled child or young person at the centre of designing, planning and delivering services for him or her
- We know how many disabled children and young people live in our area and use this knowledge when planning and designing services
- All our staff receive disability equality training and relevant staff have the appropriate specialist training and core competencies to work with disabled children
- We involve disabled children and young people in drafting our Disability Equality Scheme and also in monitoring its effectiveness at eliminating discrimination
- We involve disabled children, young people and their families in the planning, commissioning and evaluating of both specialist and universal services
- Our service plans explain how we make all universal services accessible and give details on specialist services and support, including self directed support, for disabled children, young people and their families
- Our key strategic planning documents show how we are improving outcomes for disabled children and young people
- We work closely with all relevant agency partners, especially during periods of transition
- We give disabled children, young people and their parents/carers accurate and timely information and advice on the full range of services and support available to them
- We provide a key worker service to support families in our area who are accessing more than one specialist service

Signed by

Lead Member for Children’s Services (or equivalent)  
Name of Local Authority/Health Board





© Crown copyright 2011

ISBN: 978-1-78045-053-7 (web only)

APS Group Scotland  
DPPAS11350 (02/11)

**w w w . s c o t l a n d . g o v . u k**