



for Scotland's Disabled Children
from good intentions to better lives

How we Set the Scene

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for Scotland's Disabled Children
and Young People 2009-2012

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A full set of case studies is available by contacting Contact a Family Scotland and is also being distributed to key stakeholders.



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Introduction

for Scotland's Disabled Children (fSDC) was established in 2007 to secure rights and justice for disabled children, young people and their families in Scotland. Contact a Family Scotland was one of four key disability charities working in Scotland to come together to form a campaign along the lines of that in England, "Every Disabled Child Matters". Soon a Coalition of organisations was in place, facilitating a collective voice for Scottish disability organisations. The overarching aims of the new fSDC campaign were to:

- harness families' experiences to deliver long lasting change for future generations
- challenge the system and service culture to meet disabled children's needs, flexibly and consistently
- enable good practice to flourish at local and national levels.

fSDC gained funding from the Scottish Government for a Liaison Project to address **four key issues** impacting on disabled children's lives. A task group was established for each of the four areas. Specific aims of the Project were to:

- review the **Education** (Additional Support for Learning) (Scotland) Act 2004 to ensure that it met the particular needs of disabled children and young people
- improve the provision of, and access to, **quality short breaks**
- increase and improve provision for periods of **transition**, when young people move through different phases in their lives
- improve access to better quality, affordable and appropriate **childcare** provision.

In 2009, the Liaison Project developed a Charter requesting that local authorities and health boards make their commitment to an agenda for change in how services for disabled children and their families were planned, designed and delivered. The Charter requested that local authorities and health boards:

- put the disabled child or young person at the centre of designing, planning and delivering services for him or her
- knew how many disabled children and young people lived in their area and used this knowledge when planning and designing services

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- ensured staff received disability equality training and relevant staff had the appropriate specialist training and core competencies to work with disabled children
- involved disabled children, young people and their families in the planning, commissioning and evaluating of both specialist and universal services
- had service plans which explained how they made all universal services accessible and gave details on specialist services and support, including self directed support, for disabled children, young people and their families
- had key strategic planning documents which showed how they were improving outcomes for disabled children and young people
- worked closely with all relevant agency partners, especially during periods of transition
- gave 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
- provided a key worker service to support families in their area who were accessing more than one specialist service.

Significant efforts were made by fSDC to engage with local authorities and health boards in taking forward pilots in relation to the Charter. For various reasons, however, including reorganisation of Disability Teams at a local level, it proved difficult to get firm commitment as many local authorities and health boards felt they needed additional resources to take the Charter forward.

In 2011 the Scottish Government agreed that it would consider how the principles contained within the Charter might be used within practice guidance and briefings with direct practitioners working with children on the implementation of Getting it Right for Every Child (GIRFEC). The Scottish Government is clear that many aspects of the Charter are already included in the GIRFEC approach and tools. The Scottish Government is currently developing some practice briefing for practitioners working with disabled children, to help ensure that every disabled child in Scotland reaches their potential.

The Getting it Right for Every Child approach is about how people working across all services for children, young people and adults meets the needs of children and young people. It's about making sure that leaders, managers and practitioners work together when they need to, ensuring children and young people reach their full potential.

Funding for the first phase of the Liaison Project ended in March 2012. Key areas of activity undertaken by the Project during the period 2009-2012 included:

- The Diary Project: using diaries to capture and reflect the real experiences, struggles and victories of families with disabled children
- The Conversations Project: engaging directly with children and young people to establish a snapshot of their experiences
- A survey on Quality of Life for children and young people in collaboration with Long Term Conditions Alliance, Scotland entitled "I want to be treated the same as my brothers!"¹
- The Missing Millions: campaigning to highlight issues around the lack of ring-fencing for money intended to fund services for disabled children and young people
- Analysing Single Outcome Agreements: working with local authorities to identify level of priority for outcomes relating to disability
- Conferences and workshops to raise awareness of specific issues affecting the lives of Scotland's disabled children and young people
- Supporting and enabling the fSDC Coalition meetings and building support and engagement opportunities
- Developing the work of the fSDC Coalition Task Groups and wider partnerships
- Feeding into the National Strategic Review of Services for Disabled Children.

This report presents the findings from three projects, in addition to those listed above, undertaken by the Liaison Project and grouped under the heading "Setting the Scene". Each of these projects aimed to address gaps in information which were highlighted during our work with parents, carers and professionals. The projects included:

- the creation of a website which captured, through published sources, **key data** on the number of disabled children and young people throughout Scotland and the services available to them
- **personal case studies** from the parents/carers of children and young people with disabilities about their experiences of short breaks, transition, childcare and education
- information about the availability and access to **sporting activity** for Scotland's disabled children and young people.

This report summarises the work carried out under "Setting the Scene" by describing the results and key outcomes of the three research projects.

¹ <http://www.fsd.org.uk/from-good-intentions/news/quality-of-life-research>

Our approach

Setting the Scene key data

The Liaison Project identified a lack of a central source of information relating to disabled children and young people which would assist in the design and development of services to meet their needs. To “plug” this gap, the Liaison Project sought to create a unique online resource which provided a map of disabled children in Scotland. The map aimed to:

- collate existing data about disabled children and young people
- detail local authority statistics relating to disabled children, services and resources
- provide a starting point for considering how to plan, design and deliver services and support in the future.

The first stage of the study involved designing a self-completion questionnaire for distribution to local authorities and health boards which aimed to gather key data relating to disabled children and young people in each area and the services available to them. The questionnaire was also distributed to attendees at the fSDC Conference, Getting it Right for Every Disabled Child, in May 2010 held at the Stirling Management Centre. This approach, however, elicited a poor response, despite enthusiasm amongst those attending the conference and other professionals with whom we spoke. Reasons for the poor response were:

- the data was not accessible in one place
- a “*one size fits all*” approach to data collection was not appropriate for these sectors, especially the health sector
- recipients did not have sufficient time within their busy workloads to provide data.

As data was not forthcoming through the self-completion questionnaire, the second stage involved gathering data through published sources including local authority websites and the Scottish Government website.



The “Setting the Scene” microsite was launched in November 2010 with data captured through published sources and can be accessed on www.fsd.org.uk/setting-the-scene.

A summary of the information gathered and accessible on the website is detailed in section 3 of this report.

Setting the Scene personal case studies

The fSDC website encouraged parents, young people and professionals to provide feedback on children’s experiences (both positive and negative) in Scotland in relation to four key areas – education, childcare, transition and short breaks. Individuals could complete an online form to register as a fSDC coalition supporter but could also opt to submit a personal case study, anonymously, if they wished.

Case study information was also gathered through phone discussions and through fSDC Liaison Project workshops, which were conducted throughout Scotland in 2010.

A total of 130 case studies were gathered and a Case Study Task Group was set up to identify issues raised through the case studies and to identify the gaps in evidence and support. The Group comprised parents, grandparents and practitioners thereby providing valuable insight and input to the project.

The case studies have helped to provide a background of evidence that the Liaison Project can use to influence policy in Scotland at a Parliamentary level and are featured in Section 4 of this report.

Setting the Scene sports for Scotland’s disabled children and young people

Research conducted by fSDC Liaison Project and Long Term Conditions Alliance Scotland (LTCAS) in February 2011, entitled “I want to be treated the same as my brothers!” highlighted that disabled children and young people wanted to take part in, and be supported to, participate in extra-curricular activities and have access to the same opportunities and experiences as their peers. To gain a greater understanding into what sporting activities were currently available to disabled children and young people in Scotland, fSDC commissioned independent research to determine the availability of sporting opportunities and the take up amongst disabled children and young people. To date, a web review of organisations and published data has been undertaken.

Setting the Scene key data

In this section of our report we detail the key findings from this study which are presented on the website www.fsd.org.uk/setting-the-scene. It should be noted, however, that the website has not been updated since March 2010 and that much of the data, available at that time was dated 2009. It does, therefore, present a snapshot of available data in March 2010.

Number of disabled children and young people in Scotland

- In 2009, 28,190 children aged 5-17 and 3,372 aged under five were in receipt of Disability Living Allowance in Scotland.
- 11,334 pupils were assessed or declared as disabled in Scotland's schools but due to the different ways in which data was gathered across all local authorities the information was "*not to be considered as complete*".
- The data for 2009 highlighted that there were 44,176 pupils who were either based in a special school or had Additional Support Needs (ASN) in primary or secondary schools. Of those with ASN, the main reasons for support were social, emotional and behavioural difficulties (13.7 pupils per 1,000) and learning disabilities (13.6 pupils per 1,000).
- Data gathered by local authorities and collated by health boards which record children with ASN – the Support Needs System – noted that as at August 2010 there were 14,405 children being assessed in the System. There were, however, variations in ways in which health boards gathered data.

Disabled children who were looked after, on child protection registers or in secure accommodation

- Approximately 11% of children who were classified as "*looked after*" had a disability.
- 5% of children on child protection registers at 31st March 2010 were reported as having some form of disability. 20% of all children on child protection registers, however, were reported as having "*unknown*" disability status.

- 81% of young people in secure care accommodation at 31st March 2009 had at least one known disability.
- In 2009, only 17% of disabled young people who had been "looked after" found themselves in positive destinations, such as college or in training or in employment.

Self Directed Support

- Self Directed Support (Direct Payments) to under 17s had increased from 458 in 2008 to 515 in 2010. The value for Self Directed Support (Direct Payments) to this age group had also gradually increased during that period.

Schools

- The map of special schools in Scotland highlighted that nearly 100 were located within a 50 mile radius of Glasgow and that all the seven grant-aided schools were located in Scotland's central belt. There were, however, a number of special units attached to mainstream schools located throughout the country.
- The Scottish Government's Schools Estate Statistics reported that the condition of 175 special schools or units which were open on 1 April 2010 had improved.
- In 2010/11 there were 1,913 teachers in 163 special schools in Scotland (1,985 in 2009/10) with a pupil teacher ratio of 3.6 (3.4 in 2009/2010).

The design and planning of services

- Setting the Scene identified that most local authority websites featured a Children's Service Plan and a Carers' Strategy but very few included an up-to-date Accessibility Strategy.
- Single Outcome Agreements for each local authority were in place but very few contained specific local outcomes or indicators relating to disabled children and there were no Health Efficiency Access Treatment (HEAT) targets relating directly to disabled children.

Gaps in published data

The study identified a number of gaps in available data, at that time, including:

- The levels of unmet need in each local authority area: Audit Scotland gathered and published local authority indicators on the numbers of people assessed for a service, waiting for an assessment as well as numbers of people receiving a service but this was only for adults. No such indicators were measured for children and young people.
- The number of professionals in relevant local authority departments and in health boards working with disabled children and young people, what qualifications they held and/or what training they received.
- How many disabled children and young people were in receipt of services including short breaks in their local authority area.

What the data told us...

A key finding from Setting the Scene Key Data is the need for much more accurate and comprehensive information. If we are to successfully influence outcomes for disabled children and their families, there is a need to know and understand much more about them and how services and support are currently provided. We recognise that inputs and outputs provide a very incomplete picture but it is impossible to consider outcomes without them.

Key findings from Setting the Scene identified that:

- more accurate information about the numbers of disabled children in Scotland is required.
 - there is no central collation of data at national level of unmet/met need. This is a significant omission, for example, in relation to short breaks.
 - more attention should be paid to the need to improve outcomes for disabled children in the national and local performance framework.
 - more consistent, accurate information about basic services and structures at a local level should be made available.
 - little is known about the workforce supporting families with disabled children, including if they are appropriately trained and qualified and feel competent and confident in their roles.
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- the data suggests that a national review of special education provision for children with complex needs is timely.
- more information is required about services and support and the impact these have on disabled children's lives.
- in relation to education, employment and training, outcomes are poor for young disabled people who have been looked after. There is also an under-reporting of information about looked after disabled children.
- the take-up of self-directed support for disabled children and young people remains low and the underlying causes should be examined and addressed.
- there is a disproportionate number of school exclusions among disabled children, especially those with "social, emotional or behavioural difficulties". This issue should receive further qualitative examination.
- there is an apparent "disconnect" at the transition stage between pre-school and entering school – the data suggest many children "disappear".

Setting the Scene provided a starting point for more detailed consideration of all these issues. The challenge will now be to use the collated data to provide information to policy makers to drive forward the pace of change in terms of providing better lives for disabled children, young people and their families in Scotland.

Setting the Scene personal case studies

Background to the case studies

The Liaison Project captured 130 case studies captured through the fSDC website, telephone discussions and workshops. The case studies serve as a snapshot of the key concerns raised by the parents/carers of disabled children who volunteered information relating to their experience of education, childcare, transition and short breaks.

The table below details the number of responses to each of the four key areas and highlights that the majority of comments related to parents' concerns about the needs of their disabled children within the education sector.

Key area	Number of responses
Education	61
Short breaks	31
Transition	22
Childcare	16

fSDC acknowledges that the views of disabled young people may not have been captured through this study but is actively consulting with them through the fSDC Conversations Project to identify the key issues which affect their lives.

The Conversations Project was set up in 2011 to gather views and ideas from children and young people in Scotland aged 7–25 years on five topic areas of their life. This feedback will form the basis of a report (to be published in April 2012) which will highlight their key messages to Scottish Government and inform the action plan for the National Strategic Review of Services for Disabled Children, the Children's Rights and Children's Services Bill and the Doran Review.

What parents and carers told us...

The key themes which emerged across all four priority areas – education, short breaks, transition and childcare are detailed below. Overall, the parents/carers of disabled children and young people felt that "everything is a fight and battle" with no aspect of their engagement with services/professionals as straightforward as they would have hoped. As one mother said "sometimes I have the energy for the fight but sometimes I don't".

- **Insensitivity/lack of empathy**

Parents/carers felt that the professionals with whom they met displayed, on many occasions, a distinct lack of sensitivity in their dealings with them and/or their children. Examples included parents hearing their children's diagnosis for the first time in front of professionals with whom they had had no prior contact and disabled children being excluded from school excursions, playgroups and parties.

Parents/carers described how they constantly felt like they were being "judged" by health and social professionals which impacted on their self esteem.

"Another mum whose son has ADHD was set to go on a school excursion for a week in P7. They saved up the money for the trip to be told a couple of days before that their son could not stay overnight and they would have to pick him up every night and take him back during the day. Relations with the school deteriorated after that and he ended up leaving the school."

- **Access to information**

Lack of awareness of how to access information relating to education, childcare, transition and short breaks was evident throughout the case study feedback leaving parents/carers feeling frustrated and isolated.

"Never been told about short breaks, or how to go about getting one. No support. Feels like nobody cares about my family and me."

- **Lack of flexibility displayed by local authorities/health professionals**

Parents/carers reported that the individual needs of their children were not catered for by local authorities/health professionals who wanted them to fit into their service delivery rather than customise the service to suit their needs. Comments highlighted the need for professionals to cater for the needs of a child as he/she developed and that whilst support may be relevant at one stage of their lives it may not be relevant as they grow.

"The local Council is keen to appear accommodating; however this is only when you adhere to their plan i.e. the one which requires the least work."

- **Prioritisation of the needs of disabled children**

On occasion, parents/carers felt that the needs of their families were not perceived as a priority and that other vulnerable groups appeared to attract greater support and funding.

"Financially I feel we do not receive the same support as people who are unemployed. All of these areas are based on earnings and we always seem to be earning just that little bit more than the cut off and feel that this may be the cause of your missing millions."

- **Lack of joint working and co-ordinated support**

The feedback from parents/carers highlighted the need for joint working and co-ordinated support across departments delivering services for disabled children and young people.

“Transition is a very difficult stage in an individual’s life. It involves parents/carers and a lot of partnerships working together to enable transitions to take place in the individuals own time to cope with these big changes. Communication and forward planning is vital for all involved.”

- **Lack of training for professionals**

This issue was particularly noted within the case studies relating to education with exclusion of disabled children and young people being a key concern for parents/carers. The case studies highlighted a lack of awareness, knowledge and understanding of the health conditions faced by pupils with parents concerned about the lack of staff training leaving teachers unable to cope with the challenging behaviour of some disabled pupils. The feedback from parents/carers mirrors the findings from Enable Scotland’s “Bridging the Training Gap” report² which recommended that teachers and support staff are fully trained and equipped to enable them to provide the necessary support for children and young people with learning disabilities and/or autistic spectrum disorders.

“I feel that the lack of compulsory training and understanding in schools is very worrying. I have spent years trying to educate my eldest son’s teachers, who to be fair have all been fantastic in their approach to him once I have fully informed them. However, does every parent have to personally take responsibility for teacher training?”

The case study feedback attracted feedback from a few professionals whose comments highlighted their own frustration at service delivery and the systems in place for supporting disabled children and young people.

² “Bridging the Training Gap”, ENABLE Scotland’s Teacher Education Campaign Report, March 2011

Setting the Scene sports

fSDC commissioned independent research to gain insight into how sport/physical activity was delivered to disabled children in Scotland and to identify any relevant research/data on the benefits of participation in sport/physical activity for disabled children.

The study highlighted two key reports as detailed below:

*"A literature review of the evidence base for culture, the arts and sports policy"*³ published by the Scottish Government in 2004 identified that:

- Young disabled people are far less likely to participate in extracurricular and out of school sport or physical activities than non-disabled young people.
- More than half of disabled adults felt that their disability at school had limited their participation in sport/physical activity at school.
- Almost one-fifth of disabled adults were never or only sometimes given the opportunity to participate in physical activity at school.
- More than one-fifth of disabled adults had been discouraged from taking part in physical activity at school.
- Low rates of participation in sport/physical activity amongst disabled adults are significantly influenced by their experience of sport participation at school.

A study conducted by Sport England in 2001 highlighted that young disabled people were far less likely to participate in extracurricular or out of school sport, eg 16% of the sample had taken part in extracurricular sport compared with 45% of the general sample of young people, and 47% of young disabled people had taken part in sport at the weekend compared with 74% of the overall sample of young people.

In terms of the delivery of sports/physical activity for disabled children/young people, the research commissioned by fSDC noted the range of sporting activities made available to disabled children and young people in Scotland through sportscotland's Active Schools Network and Scottish Disability Sports. Both are working in partnership with local and national organisations and volunteers to create programmes of activity.

A key issue in attending sporting activity for disabled children and young people, particularly in rural areas, is access to transport.

³ www.scotland.gov.uk/Publications/2004/08/19784/41524

A comment from a parent of a disabled child clearly highlights the role sport can play in the lives of disabled children and young people. The second comment, comes from an athlete who overcame barriers to pursue her love of sport.

“Sport is the one area of my son’s life that has been a success. Even when his mainstream education was failing he was still included and supported to take part in sports both during school hours and out of hours. We have had great support from the Active Schools Inclusion Officer in our area as well as the Royal Blind School in Edinburgh. Despite being profoundly visually impaired having cerebral palsy and an alphabet of other labels, my son is involved in various sports and outdoor education subjects in school as well as the school athletics club. He attends judo at least once a week, attends a weekly swimming club, various other sports events held by Scottish Disability Sports throughout the year and horse riding as often as we can.”

“Mainstream sport is very important but don’t forget about disabled people. I don’t think that we should have to fight for everything – we’ve got barriers in our own life. Try and make them less apparent when it comes to sport.”

Further research is required to provide more detailed information on what activities are offered to disabled children and young people as well as, more importantly, how many of them are actually able to take up these opportunities.



Other areas of Liaison Project activity

Additional reports

- The Conversations Project: A report to the Steering Group of The National Review of Services to Disabled Children and Young People - to be published on the Scottish Government website in May 2012.
 - ASL Task Group Findings Report – to be published in May 2012
www.fsd.org.uk
 - fSDC Diary Project: Final Report – to be published in May 2012
www.fsd.org.uk/blogs
 - fSDC Liaison Project Summary Report – this summary provides a condensed overview and summary of the above reports – to be published in May 2012
www.fsd.org.uk
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The online map of Scotland's disabled children can be accessed at www.fsdc.org.uk/setting-the-scene