



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

Summary Report 2009 – 2012

for Scotland's Disabled Children Liaison Project



Acknowledgements

for Scotland's Disabled Children (fSDC) Liaison Project is grateful to the many partners, families and volunteers involved in supporting the project and in particular a big thank you to the parents, children and young people who contributed to the many elements of project work over the last three years.

We are grateful to the Liaison Project Staff team for their commitment and dedication to the Project work. Particular thanks go to Ellenor Anwyl of Contact a Family Scotland without whom this work would not have been possible.

We would also like to acknowledge the Scottish Government's support in funding the fSDC Liaison Project.

Josie Isles
Contact a Family Scotland Manager
fSDC Liaison Project
c/o Contact a Family Scotland
SPACE
11 Harewood Road
Edinburgh
EH16 4NT

www.fsdc.org.uk

Index

1. Summary of Liaison Project Work	2
2. Structure of the fSDC Liaison Project	3
3. Supporting the fSDC Coalition and wider partnerships	4
4. The Missing Millions	9
5. The National Review of Services for Disabled Children and Young People	10
6. The Conversations Project	10
7. The Diary Project	11
8. How we Set the Scene for Scotland's Disabled Children and Young People	12
9. Quality of Life of Children and Young People Survey: "I want to be treated the same as my brothers!" by The Long Term Conditions Alliance, Scotland (LTCAS) and for Scotland's Disabled Children (fSDC) Liaison Project	15
10. Analysing Single Outcome Agreements for Scottish Local Government	16
11. Next Steps	16
12. Outcomes	19
Appendix 1: Key Partners	21
Appendix 2: fSDC Coalition members and Steering Group	23
Appendix 3: Reports and other research	24

1. Summary of Liaison Project Work

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. Four key disability charities working in Scotland (Contact a Family Scotland, CCNUK Scotland, Capability Scotland and Family Fund) came 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

The Coalition also identified four key areas of interest, with a task group for each of the following identified priorities:

- Short breaks
- Transitions
- Childcare provision
- Education

Consequently, the fSDC campaign gained three years of initial funding from the Scottish Government for a Liaison Project, a paid staff team to work on the issues that would take us "from good intentions to better lives".

Work on the Liaison Project commenced in February 2009 and was hosted by Contact a Family Scotland, with appointments being made for two posts by June 2009. The work was funded for three years. The Project aimed to facilitate areas of work coming under the fSDC banner, but with a focus on carrying out areas of project work rather than the broader campaigning mission of the Coalition. Key areas of liaison for the project would be with the Scottish Government's Rights and Participation Team, and with relevant Scottish Government policy and legislative development areas as well as with the Coalition and their subgroups. The Project would work in partnership, across sectors and with all relevant stakeholders, to facilitate the turning of good intentions into better lives.

The project would also facilitate more direct engagement between voluntary sector organisations and Ministers, and provide a pathway for parents and families of disabled children to feed into ongoing dialogues around service provision and development. The project also aimed to gather evidence and provide snapshots of the current situation in Scotland, providing a baseline of information for future work. Ultimately, the Project would aim to support better outcomes for disabled children, their families and their communities, working towards improving life chances for all children and young people affected by disability in Scotland.

The Liaison Project also sought to enable parents to be fully engaged with all areas of work, through a programme of parent engagement, "Three years to make a difference", which used a range of models of participation to ensure parents were enabled to inform the project on an ongoing basis.

2. Structure of the fSDC Liaison Project

Policy and Programme Support

One full time Policy Manager and one part time Policy Assistant were employed by Contact a Family, with funding from Scottish Government, to pursue the key objectives. The Contact a Family Scotland Manager had responsibility for line managing the Policy Team and overseeing the accountable resources for the Project.

Three years initial funding (April 2009 – March 2012) was awarded in 2009. Some discreet funding was also allocated for two research and engagement projects (2009 – 2012); the *Diary Project* and the Baseline Statistical Research entitled *Setting the Scene*. These are detailed within the main body of this report.

fSDC Coalition of voluntary sector organisations and parent representatives

From the outset, the Liaison Project was linked with and informed by the fSDC Coalition of voluntary sector organisations and parents who are nominated from within those organisations to attend the meetings and the task groups. There has also been some initial involvement of young people in the Coalition and the Liaison Project also sought to increase direct and supported engagement of disabled children and young people, reflecting a range of conditions. See Appendix 2 for membership of the Coalition.

The Steering Group for the Liaison Project

The Liaison Project was also guided and supported by a Steering Group, which was chaired by the Contact a Family Scotland Manager and included a Policy link from within Scottish Government Rights and Participation Team; a Coalition representative; a disability research representative and adviser from the University of Strathclyde; at least two parent representatives and two young people. The Group met with the Liaison Project every two or three months to offer support and guidance. See Appendix 2 for membership of the Steering Group.

3. Supporting the fSDC Coalition and wider partnerships

The fSDC Coalition currently meets every two months and has been gradually increasing in size and widening in focus. Parent representatives are sponsored by Coalition member organisations to attend the Coalition meetings and task groups to inform discussion and help to shape the agenda. Parents attending are supported through a host member organisation that funds their out of pocket expenses and childcare and offers training and support to enable their participation.

There are currently four Task Groups established to focus on each of the fSDC Coalition priorities:

- **Short Breaks: Improving the provision of, and access to, quality Short Breaks**

As well as providing a forum for sharing information and experience, over the duration of the Liaison Project the Short Breaks Task Group also contributed to the research aims of the project, commencing with the development and publication of the discussion paper, 'More Than a Break'. The Task Group also inputted to the consultation and survey work carried out by the project, and led a workshop on short breaks commissioning at the Supporting Disabled Children and Young People conference in Edinburgh.

Shared Care Scotland, a key member of the Coalition and chair of the Task Group worked closely with fSDC, the Family Fund and Scottish Government to establish the Better Breaks and Take a Break programmes to distribute almost £2m of Scottish Government funding in 2011/12. These programmes aim to improve short break provision to disabled children, young people and their families by supporting the development of more personalised, flexible approaches – along the lines set out in the 'More than a Break' paper.

The Liaison Project provided support to this process and led on establishing an fSDC Consultation Reference Group to offer guidance on the development of programme outcomes, priorities and application criteria, and also helped to recruit a parent volunteer to the Grants Panel for Better Breaks.

- **Education: reviewing the Education (Additional Support for Learning) Act 2004 to ensure it met the particular needs of disabled children and young people**

This Task Group has maintained a core membership throughout its existence and has been successful in contributing in a number of areas of policy and legislation in a wide range of arenas. It is currently driven by the representatives from the National Autistic Society and ENABLE Scotland, together with a parent representative from Sense Scotland. It comprises a broad range of members who are from organisations and/or parents and carers.

A central issue has been seeking to ensure the Education (Additional Support for Learning) Act 2009 meets the needs of disabled children and young people.

In partnership with the Liaison Project Policy Team, the members have been involved in collaborating around and submitting formal amendments to legislation on ASL Education, which led to changes in the final bill. The Task Group has representatives on the ASL Implementation (now Advisory) Group and the Donaldson Review Strategic Reference Group.

The Task Group recently submitted a detailed collegiate response to the Call for Evidence on the Doran Review. Members have liaised with the National Parent Forum Scotland on ASL parental representation issues and are seeking to address gaps in the representation of parents and carers.

The Task Group has supported and worked alongside ENABLE Scotland in their campaign calling for mandatory inclusion of ASL training in teacher education. This has included building an evidence base, running a petition, presenting a workshop at the SNP party conference, and providing evidence to the Public Petitions Committee and the Education and Culture Committee.

- **Transitions: increasing and improving the provision for periods of transition, when young people move through different phases in their lives**

In February 2011 an innovative partnership was formed between the fSDC Transitions Task Group and the Scottish Transitions Forum, which is facilitated by ARC Scotland. The Transitions Forum aims to improve the experience of

people with additional support needs, particularly those with high support needs, as they go through life transitions. The forum has a focus on the transition of young people from school or college to adult life. There are over 150 members of the forum including representatives from the voluntary sector, local authorities, Education, Scottish Government, young people and parents.

A consortium of partners from the Transitions Forum, led by ARC Scotland, presented a successful funding application to the Self Directed Support Fund, announced in Summer 2011 as part of the Scottish Government's National Strategy for Self-Directed Support in Scotland. The work improves the life chances of young people with additional support needs who are making the transition from school or college by increasing the capacity of providers to offer them choice, independence and control. The bid includes funding to promote the development of a Scotland wide E-forum able to reach even more families, providing information and links to support organisations, as well as briefing and policy updates for organisations involved. Some of the funding will also provide dedicated support to continue to support and expand the work of the Transitions Forum.

- **Childcare: improving access to better quality, affordable and appropriate childcare provision**

Many of the case studies submitted to the Liaison Project in the first two years have highlighted how difficult it is to find and maintain suitable and affordable childcare for disabled children. A research and training tool undertaken by Capability Scotland highlights one of these case studies – showing how childcare is often the missing link in enabling parents to work. In light of the increased focus on early years and the Early Years Fund, child care and out of school provision will become a greater priority for greater liaison in line with the Government's Carers and Child Poverty Strategies.

Each Task Group established in the last two years has a driver and short, medium and long term goals. In 2010, Task Group Drivers were chairing the wider Coalition meetings in rotation. As circumstances and needs change, a revision of processes is underway to decide the priorities and ways of working over the next three years. The Liaison Project gave more intensive support in the initial stages of setting up the new groups, and as partnerships developed the task groups have been able to function in a more self sufficient manner. From Autumn 2011 – Autumn 2012 the Family Fund is chairing and offering further support to the Coalition. Reflecting the progress made, a parent representative has been elected as vice chair, and part of this role will be to develop approaches to parent participation which can consolidate the views and engagement of parents in the work of the Coalition.

Supporters

Through the design of our fSDC website, a joint venture shared between the Liaison Project and the Coalition, we have an additional 700 supporters of the Liaison Project's work and the concerns of the Coalition. When signing up, supporters are able to select areas of interest and we are looking at how the Liaison Project can better involve this group in our work through volunteering. Supporters have learned about the existence of fSDC Liaison Project and the coalition through parent and organisation members, word-of-mouth, information and membership packs, activities, events, workshops and conferences as well as through organisations and the Diary Project. However, the single greatest reason for finding the Project is by searching online for information, support and advice. We are often reminded through the case studies submitted to us on-line, that this search often takes place amidst a crisis and many of the families that get in contact have not previously accessed any support through services or other organisations.

Conferences and Workshops

The fSDC Liaison Project has been involved in organising and delivering three Scotland-wide conferences in partnership with, and bringing together voluntary and statutory sector agencies, parents/carers and young people. Each has been attended by around 100 delegates and participants and has been planned in partnership with the Scottish Government. The conferences plot the journey of the establishment of a multi-sector Liaison Project with the power to bring people together around issues and around families:

- **9th September 2009 – Ministerial Event: the launch of “Three Years to Make a Difference” at Stirling Management Centre**

Opened by Adam Ingram, former Minister for Children and Early Years, the event launched the Diary Project and the discussions and decisions with local authorities, parents and organisations led to the development of the fSDC Charter

- **26th May 2010 – Getting it Right for Every Disabled Child at Stirling Management Centre**

Focused on the consolidation of the Charter, the challenge of getting it right for every disabled child and experiences from local authorities.

- **26th April 2011 – Supporting Disabled Children and Young People in Scotland at Surgeons Hall, Edinburgh**

Focused on the outcomes of the National Strategic Review of Services for Disabled Children, what children and young people are telling us about their quality of life and experiences and what they want from services, putting working together into action, workshops on the four Coalition priority areas and a question and answer session with politicians before the election.

In addition to three major conferences there were six workshops organised around Scotland. These were intended to raise awareness of the Liaison Project, engage parents and highlight the need for a common framework which could provide for disabled children in an inclusive way, and which gave parents and young people choices as well as better quality and levels of support.

Our Communications Strategy

HTML and Newsletters

A popular, quick and immediate communication strategy included regular HTML newsletters about the activities of the Liaison Project and Coalition in addition to new developments in our working relationship with Scottish Government. Parents in particular sign up for these updates at regular intervals. The next HTML Newsletter will go out in May 2012 which will summarise the findings and work of the Liaison Project so far and will also highlight the way forward. This is also an area of our work where we would like more children, young people and parents to get involved and support, so we can keep this fresh and relevant. We have found that parents and young people are very keen to get involved in the work of the project and are happy to contribute.

Initial Development of a hub website

Within the first year of the project an interactive website with Facebook and Twitter options, as well as sign up and links to Coalition organisations was designed, built and launched. The website originally featured the focus on the Missing Millions campaign and in June 2011 was refreshed to reflect the developments that have taken place and also in response to calls for more emphasis on involvement of young people. Highlighting research is now a priority – currently fronted by the Quality of Life Survey report called 'I Want to be Treated the Same as my Brothers'¹. The website is also updated with current research, opportunities to get involved and news from our Coalition members.

Informing discussions through Cross Party Groups

The Liaison Project has been attending the Disability and Children and Young People Cross Party Group meetings since the beginning of the project. In October 2010 a staff member of the Liaison Project gave a presentation, to a joint meeting of the two groups, on the work of the project. As part of the presentation a parent and a young person from the fSDC Liaison Project Steering Group spoke about their own personal experiences, why they became involved in fSDC and highlighted what they would like changed. Attendance at these party groups continues and especially aims to highlight wellbeing issues.

4. The Missing Millions

In 2009, the first of the large pieces of work to be offered support by the Liaison Project was a campaign to establish what had happened to £34m of consequential money that came to Scotland from England, as a result of *Aiming High for Disabled Children: Better Support for Families*, an English Government strategy for supporting disabled children and their families, with associated funding.

The consequential figure for Scotland was £34 million, which, in accordance with the Concordat, was absorbed into the local government budgets and was not ring fenced. The fSDC Coalition Missing Millions Campaign highlighted issues related to the Barnett Consequential Formula, as well as the vulnerability of budgets no longer ring fenced (or where ring fencing may never have been applied) to redirection into other local authority priority areas. Thirty seven MSPs signed up in support of the campaign, from across various political parties, as well as two MPs, Tom Clarke and Russell Brown, and individual local authorities also submitted responses. Lessons learned from this joint working and effort to place disabled children's needs firmly on the map have been heard across Government, and an example of this is in the ring fencing of the £2m for short breaks provision for disabled children in 2011-12, consequential funding from the abandonment of the Child Trust Fund. Through joint working between the Liaison Project, fSDC member organisations and the Scottish Government this funding was distributed directly to families and to third sector short break services to help them develop their provision.

5. The National Review of Services for Disabled Children and Young People

Between 2010 – 2011 fSDC Liaison Project and the Scottish Government worked together with other partners to lead a review of services for disabled children and their families across Scotland. The fSDC Liaison Project was closely involved in developing the Review Report. The Review was intended to assess the state of play, identify areas of concern, lay out current data and reflect on the monitoring of such services. An Action Plan was drawn up, containing 15 actions designed to improve services for disabled children and young people. The majority of the actions are for Scottish Government to take forward, in conjunction with partners. The Liaison project supported the implementation of the action plan by coordinating further consultation with children and young people on some of the key areas covered by the review through the Conversations Project, detailed below.

The National Review Group reformed in August 2011 and is in place until April 2012 to monitor and advise on the implementation of the actions in the action plan. A Progress Report² will be published by the group in Spring 2012.

6. The Conversations Project

In August 2011, as part of the National Review of Services to Disabled Children, the Chair of the Steering Group, Harriet Dempster, set up a small working group tasked to consult disabled children and young people about their priorities and experiences, in light of the Review's Action Plan which had been published in February 2011. fSDC Liaison Project took an initial lead in this work, organising data collection through 10 organisations, mostly in the form of focus groups or face to face interviews. In all, 66 young people took part. They were aged between 9 and 22 and a majority were male (39).

The young people spoke positively about many positive aspects of their lives. The majority reported having sufficient opportunities to express their views, although this may reflect the method of recruitment, largely through existing groups and unlikely to be typical of all disabled young people. However, many also reported feelings of isolation and spoke of difficulties in making and maintaining friendships including, for some, at school. Participants identified a range of barriers in their lives, such as lack of accessible transport, unmet needs for personal support, not feeling safe in their local area, and physical and attitudinal barriers. The findings also highlight a need for young people to have more information about what options are available to them in the

future, in terms of achieving greater independence and a range of work opportunities.

The Conversations Project report³ will be published on the Scottish Government website in May 2012 alongside the Progress Report on the National Review Group.

7. The Diary Project

The Diary Project went live in Spring 2010 after a conference based launch. A unique grant was awarded by Scottish Government and it has always been an expectation and commitment given that the family and individual experiences accumulated through the blogs and diaries would be shared with Ministers, the fSDC Coalition Task Groups, Local Authority Disability Leads and Health Boards, along with the wide range of Case Studies and other evidence collected through the Liaison Project and Coalition Members.

The project was initiated by parents, for families as an innovative way of:

- capturing and reflecting the real experiences, struggles and victories of families with disabled children;
- overcoming geographical barriers to engage parents with the Liaison Project so that they can be more directly connected to Ministers and policy makers;
- enabling connections between families and thereby building networks of mutual support;
- providing the opportunity for young disabled people to convey their experiences about growing up in Scotland today;
- piloting the uses of social networking tools for offering support and to harness experiences as part of the Government's consultation and participation strategies.

A range of methods were available to participants to record their diaries including blog, visual diaries, audio diaries and written testaments. The Liaison Project has been able to use the Diary Project as a means by which we can gain more insight into particular experiences, barriers or opportunities: experiences of access to sport and leisure, for instance.

The full Diary Project report⁴ details the recruitment and induction of families, events held, details of family characteristics, and also identifies emerging themes. All participants found the Diary Project to be a highly valuable resource and made a series of suggestions for future initiatives building on

this initial pilot phase, detailed in the Report. It was felt by all that the Diary Project was very much an ergonomic, “growing” resource and it adapted and developed its own direction as situations, experiences and policy in Scotland changed. It also provided a channel for young disabled children and their families to inform ongoing developments in policy at a national level. Participants were keen to see a second phase of the work to date, focussing on the suggested initiatives.

The DVD, created by project participants, also highlights the merits of blogging and enables young disabled people in particular to express not only the issues and barriers they encounter in their own lives but also their hopes for other young people in the future. The DVD⁵ complements the Diary Project report and is available to view on www.fsd.org.uk/blogs.

8. How we Set the Scene for Scotland’s Disabled Children and Young People⁶

This report summarises the work carried out under “Setting the Scene”. Each of the projects aimed to address gaps in information which were highlighted during our work with parents, carers and professionals. The full report describes the results and key outcomes of the following projects:

The fSDC Charter

In 2009, the Liaison Project developed a Charter⁷ 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.

A Charter discussed and selected in partnership with local authorities, health boards and parents was finally agreed in 2010. There are ten commitments reflecting the minimum requirements for delivering a good standard of services for families with at least one disabled child, detailed in the above report.

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 they would consider how the principles contained within the Charter might be used within practice guidance and briefings which direct practitioners working with children

on the implementation of Getting it Right for Every Child (GIRFEC). Scottish Government is clear that many aspects of the Charter are already included in the GIRFEC approach and tools.

This will also lead to good practice and the possibility of a conference focusing on the principles and how they are implemented will be discussed with Scottish Government GIRFEC colleagues, through the implementation of the Review Action Plan where it is sited. The Charter is also cited as an example of good practice in meeting children's rights under the UN Convention on the Rights of the Child and will be discussed again across the Coalition as they move forward.

Key Data

In early 2010, the Liaison Project undertook the first stages of a research project in partnership with Scotinform. 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.

Across local authorities FOIs were submitted in order to collect the range of data collected. The picture was quite fragmented and in some cases useful data was not collected by all authorities and therefore could not be included in the statistical analysis. A second stage of the project involved gathering data through published sources including local authority websites and the Scottish Government website.

The *Setting the Scene*⁸ microsite was launched in November 2010 with data captured through published sources.

Setting the Scene provided a starting point for more detailed consideration of all these issues. The challenge will now be to build upon this 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.

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 the four priority 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, by email and through fSDC Liaison Project workshops and events, which were conducted throughout Scotland in 2010.

A total of 130 case studies were gathered and a short term 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 Task 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. Further detail on the key emerging themes can be found in the full *How we set the Scene* Report.

Sports

Quality of Life of Children and Young People Research conducted by The Long Term Conditions Alliance, Scotland (LTCAS) and fSDC Liaison Project 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.

In terms of the delivery of sports/physical activity for disabled children or 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.

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.

9. Quality of Life of Children and Young People Survey: "I want to be treated the same as my brothers!"

by The Long Term Conditions Alliance, Scotland and for Scotland's Disabled Children Liaison Project

This piece of research was commissioned jointly by the fSDC Liaison Project and The Long Term Conditions Alliance Scotland (LTCAS) following a young people's summit entitled "Seen but not Heard". The work was largely carried out by Scotinform. The findings were compared with results from a European study of 20,000 children, mostly non-disabled. The survey had used the same questionnaire (KIDSCREEN) and a Youth Link Survey of 2000 primarily non-disabled children in Scotland. Setting the findings in this wider context was a particular strength of this study.

The children in the sample were all either disabled or had long-term conditions enabling comparison between the emotional well-being of disabled children and their 'non-disabled' peers. We asked them to let us know about their main concerns. Issues highlighted were lower emotional wellbeing on average, more isolation and loneliness, fewer friends and access to make friends, less access and choice of a range of leisure activities, as well as a need for opportunities to develop more independence. However, the research did show that the majority of children had more upbeat perceptions of their lives, for example:

43% of respondents had found their life in the past week 'very' or 'extremely' enjoyable and a similar percentage said they had 'very often' or 'always' been in a good mood and had fun. Being at school was the most positive area for respondents, with approximately half saying they were very or extremely happy there.

The report was published in February 2011 and was presented by Professor Kirsten Stalker, University of Strathclyde at the April conference. The full report is available on both fSDC and LTCAS websites.

10. Analysing Single Outcome Agreements for Scottish Local Government

Working collaboratively with partners from across the Children's Voluntary Sector Policy Officers' Network, the fSDC Policy Manager undertook an analysis of Single Outcome Agreements (SOAs) across 32 Scottish local authorities to identify how many had selected an indicator for measuring outcomes related to disability. The analysis highlighted that very few included this as a priority in their area and prompts the need for a greater focus on measures and indicators for monitoring of outcomes for disabled children. A report was produced on the extent to which children's issues, covering a total of 19 themes, had been addressed and prioritised in the SOAs for 2009 – 2010. Whilst it was recognised that the voluntary sector plays an important role as a service provider and strategic partner, it was recommended that those responsible for developing future SOAs ensure that all children in Scotland and their families receive appropriate and adequate services so that our children can reach their fullest potential. A report by the Children's Voluntary Sector Policy Officers' Network, *Single Outcome Agreements for Scottish Local Government 2009 – 2010: a thematic analysis* gives further detail.

11. Next Steps

Collaborative Development

The future of the Liaison Project was considered by all relevant stakeholders during a Collaborative Development Day held in January 2012 and facilitated by CELCIS, the Centre for Excellence for Looked after Children in Scotland. The purpose of the day was to lay the groundwork for a proposal for the future of the Liaison Project work. The report¹⁰ details participants and activities, and identifies a number of "asks" and priorities for future areas of work.

Asks included:

- Prioritising the needs of the key Liaison Project stakeholders (currently these are the Scottish Government and Disabled Children)
- Supporting the Government's attempts to "get it right" in all areas
- Ensuring the voices of parents and children are heard
- Profile raising of relevant issues

Proposed activities included:

- Direct consultation with disabled children
- Indirect consultation via Coalition partners
- Promotion of the Liaison Project
- Evaluating the impact of the Liaison Project

Inherent in the discussions was a requirement to develop and maintain a close working relationship with the Scottish Government, with some consideration to be given to periods of residency or partial co-location within the Scottish Government to establish stronger links.

Participants were also clear that the governance arrangements for the Liaison Project needed to be revised and considered a number of alternative models. Clear terms of reference were also needed to highlight decision making arrangements and clarify the relationship between the Liaison Project and the Coalition, enhancing and strengthening links.

It was also felt that a model of stakeholder engagement could be developed, ensuring meaningful engagement in particular for disabled children and their parents, as well as the organisations and partners working in partnership with them. Participants felt it was important to remember the main purpose of stakeholder engagement was to enable disabled children, young people and their families to have a strong, persuasive voice to influence policy directly.

Fun and Friendship for disabled children and their families

In response to the Quality of Life Report detailed on page 15, a new strand of work focusing on emotional wellbeing, reducing isolation and promoting networks of friendship and access to leisure was considered. It has been proposed that a steering group of organisations pull together to shape the programme and the priorities on which it could focus. This strand of work could be a key aspect of working to support life chances and citizenship for disabled children and young people.

As the fSDC sports research highlights, there could also be a focus on improving sports and leisure opportunities for disabled children and young people to feed into the Commonwealth Games and raise the profile of the potential held by all children and young people. The UN Convention on the Rights of the Child (UNCRC)¹¹ highlights children's right to participate under articles 12 and 13.

Also, by involving young disabled people in a wider scope of activities and social networks we will be supporting all round experiences, greater confidence and independence and better outcomes across the board. It would go a long way towards breaking down barriers and attitudes which restrict disabled children and young people and improving the overall health and wellbeing of children and their families.

Disabled children and young people's views and voices

The Liaison Project also proposes the development of a National Young Disabled People's Forum in Scotland in conjunction with Scotland's Commissioner for Children and Young People (SCYPP) sited with an appropriate voluntary organisation for children and young people. This could advise the Commissioner and be available to service planners and providers at local and national level as an advisory group. It could, importantly, identify its own issues and priorities. The forum could also reflect the Fun and Friendship strand focusing on promoting wellbeing and friendship networks, as well as input into resilience projects such as anti-bullying projects in schools.

It was also hoped that a second phase of the Diary Project focuses more closely on young people as participants and offers young people volunteering opportunities within the Liaison Project and the Diary Project itself as it develops. This exciting aspect of the way ahead fits closely with the Scottish Government priorities – particularly engagement with and participation of children and young people.

Parent's views and voices

A next phase of work could also be taken forward to provide a National Parenting Forum and other ways of engaging effectively with parents at all levels, facilitating a variety of ways in which they can get involved with a range of opportunities for contributing and moving towards a new model for parent participation and partnership.

Partnership working

The positive outcomes that the Liaison Project has achieved have often been due to the collaborative partnerships developed between voluntary sector organisations and across other sectors, as noted in **Appendix 1**. Next steps might include formalising partnership arrangements with stakeholders, particularly the Scottish Government.

12. Outcomes

The participants of the development day all agreed that further detailed work was needed to identify clear outcomes and the indicators that would illustrate the impact of the changes that came about as a result of the project work carried out. Much of the work carried out had set a baseline or given a snapshot of issues, and developing indicators against which progress towards the outcomes could be gauged would strengthen work and give robust evaluation information.

Participants identified a number of outcomes from the project work which are detailed in the report on the Collaborative Development Day. Stakeholders mapped the current work of the Liaison Project against the GIRFEC Wellbeing Indicators and the National Performance Framework Outcomes. The development day report listed in Appendix 3 illustrates where this list of Liaison Project Outcomes relates to these national outcomes and indicators. It is interesting to note that stakeholders considered many of these indicators and outcomes to link strongly with the work of the Liaison Project and could identify links between different areas of Government priority.

Individual project areas had their own outcomes, depending on the stakeholders the Liaison Project was working with. For example, the Diary Project had particular impact for disabled children and families. Broader outcomes of the Diary Project work had included:

- Families feeling less isolated
- Families feeling more confident that they could find the right support for their child
- Families linking and supporting one another
- Young disabled children feeling more included and consulted about decisions that would affect them
- Decision makers felt more informed about the needs and concerns of the people they were developing policy for.

In the Diary Project, the importance of issues like emotional support at times of crisis were seen by participants as key to improving the experiences of families supporting disabled children. Ultimately such preventative measures as these would have an impact on these two particular National Performance Framework Outcomes:

- Our children have the best start in life and are ready to succeed
- We have improved the life chances for children, young people and families at risk

However, the Project also had clear outcomes in the development of partnership working and working effectively with the Scottish Government. Similarly, and more indirectly, communities were being strengthened and building peer support, relating closely to the National Performance Framework Outcome:

- We have strong, resilient and supportive communities where people take responsibility for their own actions and how they affect others

In 2005 the Vision for *Getting it right for every child*, stated that Scotland's children and young people should be *successful learners, confident individuals, effective contributors* and *responsible citizens*. In order to achieve this, children and young people needed to be *safe, healthy, achieving, nurtured, active, respected, responsible* and *included* (initially referred to as SHANARRI indicators and now more generally known as the Government's eight Well-being Indicators¹²).

A useful next step in continuing work would be to work more closely with the SHANARRI indicators and measurement set of indicators linked to the National Performance Framework, pinpointing where each area of project work was having an impact, and developing an appropriate Outcome and Evaluation Framework.

There is still much scope to build on the learning and work carried out by the Liaison Project over the last three years. Longer term outcomes of the project work are clearly related to:

- Empowering disabled children, parents and families to engage confidently at all levels, particularly through effective consultation on developing policy and legislation
- Improving the health and wellbeing of disabled children, parents and families
- Removing barriers that exist for disabled children, parents and families
- Improving practitioners' ability to provide preventative and anticipatory (as well as responsive) services and support

The broad range of outputs from the Liaison Project ultimately go a long way towards moving the landscape for disabled children and their wider communities from good intentions to better lives.

Appendix 1: Key Partners

The project established a wide range of partnerships in only three years. Many of the partnerships and links hold significant potential for taking forward successful and coherent work in 2012 – 2015 which can support the changes required to enable every child to develop and fulfil their aspirations and potential. Appendix 1 of this report outlines the partnerships developed to date.

Partner	Development Policy Outcome
<p>From an original 4 key organisations in 2007: Contact A Family, Scotland; The Family Fund, Scotland; CCNUK, Scotland; and, Capability Scotland</p> <p>2009 – 2011 has grown to 46 voluntary sector organisations who are members, plus individual parents</p>	<p>Cross-sector engagement, consultation and working;</p> <p>Greater communication and partnership working with parents;</p> <p>Greater potential for coherence across the agenda;</p> <p>Coordinated responses to Government consultations; and,</p> <p>membership on key boards and groups.</p>
<p>A range of other voluntary sector organisations for particular pieces of work outside the Coalition: Children in Scotland, Enquire, Chip +, RNIB Haggeye, Perth and District YMCA and Youthlink</p>	<p>Synergise aims and increase communications and potential coherence</p> <p>Achieve aims and reduce duplication</p> <p>Increase reach and geographical spread</p>
<p>COSLA</p> <p>Local Authorities</p> <p>Health Boards</p>	<p>Develop dialogue towards joint working to improve practice and planning</p> <p>Take forward the fSDC Charter</p> <p>Delivery of Scotland wide conferences</p> <p>National Strategic Review of Services for Disabled Children</p>
<p>Scotland's Commissioner for Children and Young People (SCCYP)</p>	<p>Partnership working to support the Commissioner's a RIGHT blether consultation and priority of Disabled Children</p>
<p>Together Alliance, Scotland</p>	<p>Support gathering evidence for and reporting on the UNCRC and UNCDRP</p>

<p>The Scottish Transition Forum (around 40 members); and, The Scottish Transition E-Forum</p>	<p>With the support of the Liaison Project the Forum submitted a bid to the Self Directed Support Fund 2011 – 2012 for development of a Transitions Information Exchange</p>
<p>Long Term Conditions Alliance, Scotland (LTCAS)</p>	<p>Quality of Life Research with Children and Young People Continue Self Managed opportunities</p>
<p>Glasgow and Edinburgh Universities</p>	<p>Establish effective baseline information and gain first class advice on research with children and families</p>
<p>Scotinform</p>	<p>Undertook baseline research, delivered reports and now to develop against the potential of the initial remit Initiated an enquiry into sports and leisure access in order to work with Conducted the Quality of Life Research</p>
<p>Indigo Project Solutions and the Graphics Company</p>	<p>Development of website, Diary Project and social networking opportunities and communications</p>
<p>Creative Scotland and associated projects</p>	<p>Develop the fun and friendship, emotional well being and citizenship strands in response to children and young people</p>
<p>The Scotland Policy Officer Networks Cross Party Groups</p>	<p>SOA analysis Information Exchange Direct information and presentation from parents and young people</p>
<p>BBC Scotland, Media Trust UK and Community Service Volunteer Training Services</p>	<p>Media development with young people Working with the media to highlight parents and young peoples concerns</p>
<p>Contact A Family, UK – including Wales and Northern Ireland Nation Projects Every Disabled Child Matters and the Council for Disabled Children, England</p>	<p>Benefit from UK wide initiatives and to coordinate with Westminster in response to concerns of parents and children and young people in Scotland</p>
<p>CELCIS</p>	<p>Facilitated the Collaborative Development Day and developed a report on the future of the Liaison Project on behalf of all stakeholders</p>

Appendix 2: fSDC Coalition members and Steering Group

fSDC Coaliton Members

Aberlour Childcare Trust	Genetic Interest Group
Action for Children	Keys to Inclusion
Action for Sick Children (Scotland)	KIDS
Archway (Respite Care & Housing)	Kindred
Arran Parents Support Group	Mindroom
Association for Real Change (ARC Scotland)	National Autistic Society (NAS) Scotland
Autism Treatment Trust	National Deaf Children's Society (NDCS)
Barnardo's Scotland	One Parent Families Scotland
Capability Scotland	PAGES
Carers Poverty Alliance	PAMIS
Caring Operations Joint Action Council (COJAK)	Parent Inclusion Network (PIN)
Common Ground Mediation	PLUS
CCNUK/LTCAS	PRT Borders Carers Centre
CHIP+	Quarriers
Contact a Family Scotland	RNIB
Downs Syndrome Scotland	Scottish Alliance for Children's Rights (Together)
Dumfries and Galloway Carers	Scottish Disability Equality Forum (SDEF)
Dyslexia Scotland	Scottish Society for Autism
East Dunbartonshire Carers Link	Scottish Spina Bifida Association
Eczema Scotland	Sense Scotland
ENABLE Scotland	Shared Care Scotland
Epilepsy Scotland	Signpost
Family Fund	Sleep Scotland
Friends of Midlothian's Children	

Steering Group Members (as of March 2012)

Josie Isles, Contact a Family, Scotland Manager (Chair)
 Don Williamson, Chief Executive, Shared Care Scotland
 Laura Guthrie, Young Person Adviser
 Adam Stafford, Young Person Adviser
 Kirsten Stalker, Professor of Disability Studies, University of Strathclyde
 Sam Medley, Parent Adviser
 Kathleen Mathieson, Parent Adviser

Appendix 3

Reports and other research

1. "I want to be Treated the Same as my Brothers" Quality of Life of Children and Young People Survey Report by The Long Term Conditions Alliance, Scotland and for Scotland's Disabled Children Liaison Project
www.fsd.org.uk/from-good-intentions/news/quality-of-life-research
2. The National Review of Services for Disabled Children and Young People report – to be published in May 2012 on the Scottish Government website
3. 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.

A short, accessible summary is also available.
4. fSDC Diary Project: Final Report – to be published in May 2012
www.fsd.org.uk/blogs
5. fSDC Diary Project DVD: available on the fSDC website in May 2012
www.fsd.org.uk/blogs
6. How we Set the Scene for Scotland's Disabled Children and Young People 2009-2012 – to be published in May 2012 **www.fsd.org.uk**
7. fSDC Charter – available to view on **www.fsd.org.uk/to-better-lives**
8. Setting the Scene – online resource **www.fsd.org.uk/setting-the-scene** and printed report available to download from **www.fsd.org.uk/setting-the-scene/intro**
9. Single Outcome Agreements for Scottish Local Government 2009-2012: a thematic analysis **www.youthlinkscotland.org/Index.asp?MainID=7716**
10. fSDC Liaison Project Collaborative Development Day report – produced by the Centre for Excellence for Looked after Children in Scotland (CELCIS) to be published in May 2012 **www.fsd.org.uk**
11. UN Convention on the Rights of the Child – further information from **www.togetherscotland.org.uk/about-childrens-rights/un-convention-on-the-rights-of-the-child/**
12. GIRFEC Wellbeing Indicators and the National Performance Framework Outcomes – **www.scotland.gov.uk/Publications/2007/11/13092240/9**

for Scotland's Disabled Children



For more information please contact:

fSDC Liaison Project
c/o Contact a Family Scotland
SPACE
11 Harewood Road
Edinburgh
EH16 4NT

0131 659 2939

info@fsdc.org.uk

www.fsdc.org.uk