



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



**For Scotland's Disabled Children Liaison Project  
Diary Project - Interim Report  
February 2011**

# Diary Project – Interim Report

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## Acknowledgements

for Scotland's Disabled Children Liaison Project would like to thank all the participants of the fSDC Diary Project for taking part. We would also like to acknowledge the Scottish Government's support in funding the Diary Project.

Cover photograph - Magali Bisson and family

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# 1. Background to Project

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In 2009 for Scotland's Disabled Children (fSDC) Liaison Project launched its parent engagement programme, called "Three years to make a difference". Parents of disabled children told fSDC that they want things to be different. But what does "different" look like? If they had a blank sheet and could design a social care system that provided the right support for their child (and the rest of the family) in the right way at the right time - what would that system look like? And how do we turn a dream into reality - how do we promote "different" to the agencies and professionals and then work with them to make it happen? The programme aims to determine what "different" looks like and then work out how to make "different" happen.

"Three years to make a difference" uses a range of methods to engage with parents, carers and young people so that they are central to the process of change. One of the innovative ways established was a diary project which would allow and encourage parents and other family members to share their thoughts and experiences with us. Not just about the trials and tribulations of being a "disabled family", as one parent put it, and the problems and issues they encounter when trying to access services and support for their child. But also, to tell us about the joys, exasperations and hopes that ordinary family life entails, to get across that they are parents just like any others. The project also gives young disabled people the opportunity to talk about their experience of growing up in Scotland. Crucially we want diary participants to map their progress on the journey to find "different" and make it happen.

The fSDC Liaison Project wanted to try to reach and involve many of the "hidden" families and give them a voice. Everyone acknowledges that there are many families out there that no one ever hears from. So our project will involve individuals from a wide range of backgrounds and geographical areas. It will also involve families where children have a range of impairments and support needs and whose children are at different ages, in addition to parents in different family circumstances, such as lone parents, kinship carers and foster carers.

Participants are encouraged to choose the diary method that best suited them: online blog, paper, visual or audio. Training, mentoring and support are provided by Indigo Project Solutions throughout the project lifetime.

Diary findings will be collated and shared anonymously with key decision makers in Scottish Government, at local and central level and used to influence the change process at the heart of the liaison project's work.

Online blogs are published at [www.fsd.org.uk/blogs](http://www.fsd.org.uk/blogs)

fSDC has recruited Indigo Project Solutions Ltd, based in Edinburgh, to manage the project on our behalf. Indigo works closely with the fSDC Liaison Project to ensure that the diary project objectives are met and that the necessary support is provided to the families involved.

## 2. Recruitment and Induction of Families

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Recruitment for the project started in April 2010, with participants beginning their diaries in July 2010. Participants were recruited via a range of organisations and sources including;

- fSDC and Contact a Family Scotland members and contacts
- Indigo's database of contacts
- Asking support organisations working with disabled children to help to promote the project. Organisations included Enable Scotland, Sense Scotland, The Fostering Network Scotland, Sibs, Changing Faces, Quarriers, Scottish Spina Bifida Association, and Ethnic Enable
- Contacting special needs schools throughout Scotland by email (approx 100)
- Advertising through Third Force News and eNews, Sense Scotland, and Centres for Voluntary Services such as Renfrewshire CVS, West Dunbartonshire CVS, Aberdeen CVO, and Glasgow CVS
- Social media announcements on twitter and facebook and news articles on [www.indigops.com](http://www.indigops.com) and via fSDC [www.fsd.org.uk](http://www.fsd.org.uk)

An induction meeting was organised to help initiate people into the project and to give guidance on how the project would work. The event took place at Donaldson's (Scotland's national school for pupils who are deaf or have communication difficulties) in Linlithgow on Saturday 28<sup>th</sup> August 2010. The event, which took place from 11.00am – 3.00pm, began with an informal introduction to the project, giving participants background information about its aims and target outcomes, and giving the families a chance to meet the staff who would be supporting them throughout the project. Participants were given hands-on tuition using the equipment. Families were encouraged to network with each other over lunch and to get to know the others involved in the project. Specialist childcare was provided at the event to allow the whole family to come along and get involved.

One participant said 'the atmosphere at the event was one of excitement. It was a great opportunity to put faces to names, meet other parents to share stories and experiences, as well as putting a more 'human' aspect to names on blogs as we go forward'.

Another participant mentioned that she 'loves how accessible the project is to people, so many different ways to help people to get their story out, limited only by imagination'.

Kate Higgins, former Policy Manager at fSDC Liaison Project, said 'The induction day was about giving diary participants the chance to find out more about the project, and consider different ways of keeping their diaries. The most important aim was to give people the chance to meet other diarists, and find out what motivated them to get involved.'

The families taking part in the project all agreed that raising a disabled child can be a struggle, and it was clear at the induction event that the parents and carers would be supporting each other going forward through their diary blogs.

A mother commented, 'It was wonderful to come along on Saturday, I'm so glad I made it! I met some wonderful people, like the staff involved in the project, but most importantly I met other parents and children who are feeling exactly the same as us. I came along on Saturday feeling alone and scared and wondering if I was doing the right thing. I left the induction feeling like a new person, I felt like I had met family that I had not seen in a while, it was wonderful and I knew then that taking part in the Diary Project was absolutely the right thing because all the empty and lonely feelings disappeared and was replaced by warm, friendly feelings, so if any of my blogs can do that to even one person reading them then it's all been worth it. I have not felt this excited about anything in a long time!'

The families involved in the project were keen to make sure their experiences make a difference going forward.

Another mother commented 'we all need to see something come of this, a 'greater good', over and above being able to support each other - we will feel we ALL contributed to something that way'.

Kate Higgins added 'fSDC's role is to make sure the wider world is hearing the families' stories and that these experiences are reaching those that design and plan services. Their diaries will help us make change happen'.

The project is promoted on an ongoing basis through social media as new blogs are uploaded, i.e. a tweet is sent out with a link to the new blog on twitter and a message is also posted on facebook.

### **3. Motivations for Participation**

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The families involved in the project have cited a variety of reasons for wanting to take part. These included:

- to share their experiences with other people
- to hear how other families cope in similar circumstances
- a way of venting frustration
- a positive way of changing things for the better
- to give and receive support from other families participating in the project
- to develop a guide to their child's disability which they can give to professionals to alleviate the need to go into long descriptions in person each time they meet a new medical or educational specialist
- to use as a book for publication at a further date
- to help change government policy and to encourage improvements for the future
- make connections with other families.

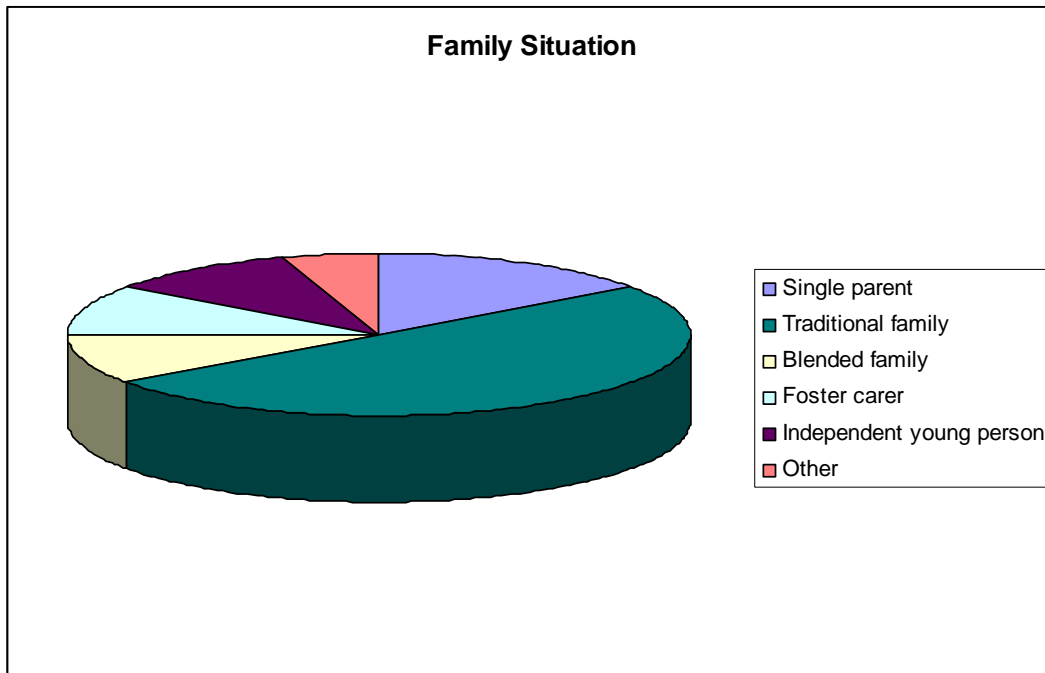
## 4. Family Characteristics

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Project participants range widely in terms of personal characteristics. The children and young people range in age from 1 year old to 22 years old and their disabilities include:

- ADHD
- Angelman syndrome
- ASD
- Aspergers
- Asthma
- Autism
- Autistic Spectrum Disorder
- Blindness
- Brain damage
- Cerebral Palsy
- Chromosome 18 Ring
- Down Syndrome
- Dyspraxia
- Eczema
- Epilepsy
- Hypothyroidism
- Irritable bladder syndrome
- Juvenile arthritis
- Learning disability
- Lowe Syndrome
- Maple syrup disease
- No speech
- Noonan Syndrome
- Pan colitis
- Schizoaffective Disorder
- Seizures
- Sensory impairments
- Spinal curvature
- Spinal Muscular Atrophy

Fifty percent of participants have a traditional family structure, i.e. 2 parents and children. 15% of participants are single parents; 10% are blended families, i.e. with one step parent; 10% are foster carers, and 10% of participants are independent young people. 5% are classified as 'other' which includes a child living in a residential school for "troubled and troublesome" young people.



There is also a cross section of participants in terms of geographical locations encompassing the following local authorities:

- Ayrshire
- Dumfries & Galloway
- Edinburgh
- Falkirk
- Fife
- Glasgow
- Highland
- North Lanarkshire
- Renfrewshire
- Scottish Borders
- West Dunbartonshire
- West Lothian

Most participants have chosen to complete their diaries through online blog although a few have chosen to do traditional paper diaries.

## 5. Emerging themes of diaries

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We have monitored the diaries and have picked a number of recurrent themes to highlight within this report. There are many diary entries on other themes but these have attracted most comment so far.

- How families found out about their child's disability/illness
- Medical and care challenges
- Relationships
- Aspirations.

Please note, pseudonyms have been used in order to respect the privacy of the project participants.

### How families found out about their child's disability/illness

This is obviously a very important and emotional time for the families and many have started writing their diaries at this point.

- I. Mandy and Rebecca are twins... born 3 months early (and I still remember how small and frail they were). I had difficulties with Rebecca when they arrived so early, and to save her, Mandy had to be 'taken out' first. No-one will ever know if the Cerebral Palsy happened before birth, or as a result of decisions that had to be made immediately to save Rebecca
- II. Me and my younger sister were born with classic Maple Syrup Urine Disease. She was diagnosed pre-natally, but I, being the oldest, wasn't diagnosed until fourteen months. MSUD is a genetic disorder.
- III. After trying for a baby for some time, it was felt our best chance of conceiving would be IVF, so after 2 cycles we were given the best news in the world that we were pregnant, the following month at our first scan showed it was twins! I gave birth to Heather first, she was taken away and ventilated and taken to intensive care, 50 minutes later wee Kelly was born, there was no

noise when they told me I had another wee girl, it was silence! They both weighed 2lbs. The next thing I knew she was taken in an incubator up to intensive care, while I was taken to recovery. As a result of the traumatic birth Kelly had, and the fact I was not given a section, wee Kelly suffered brain damage (PVL). A lot happened in the following weeks, Heather grew stronger while Kelly didn't, it was in these weeks that we were told Kelly had Quadriplegic Cerebral Palsy, Bulbar Palsy (no swallow/suck).

## Medical and care challenges

This theme comes up the most regularly and is the issue that obviously concerns parents the most.

- I. More than a few months ago I contacted the local incontinence service to discuss the product James uses... The lady declared that it was probably better for James to use a smaller size pad and she would sort us out some to try. Well, the samples never appeared... Incontinence services up and down the UK are notoriously oppositional. More than many parents and patients, I suspect, sympathise and understand that there is a budget to stick to. James' allocation is more than most because of his medical background and had to be backed up by a letter from the school paediatrician... No service level agreement, no checks with users about how the service is going for them, no clear path as to who to complain to if the service is going wrong. We had a meeting at the school hosted by the then incontinence advisor to allay fears about the new product, she came out with this pearler.. ( conversation paraphrased as far as I can remember it ) "when you take the pad off for your child to try using the toilet, and it's not too wet, you can put it back on them afterwards". The last delivery of pads to our house at the end of August. We got a letter this morning dated the 15th Oct saying 'We don't have supplies of your product, and we apologise for the inconvenience'. I'm sending this to the blog at 2pm on Thursday 21st Oct and I still have no forecast from our incontinence service as to when James daytime pads will appear with them or with us. So during this October school break, we are confined to the house until they appear. That's how I like to spend my precious time...waiting for help.
- II. I have been registered with the same GP for 6 years now so this means he has known Grace all her life, referring her to many dermatologists, prescribing all sorts of specialist treatments and equipment over the past 5 years (our

repeat prescription is huge), witnessing her infections and distress, her bleeding baby face and her scabby hands more recently. The recent discussion between us went as follow:

-“Hello, I've come to discuss a referral for my daughter Grace (then I explained why, how, how much etc).’

- (He smiles gently although some may use the word 'patronisingly') Oh but I am really sorry, I cannot do that. You see, this OT service is not for everyone, it is specifically for people with disabilities so you couldn't possibly be eligible.

- But Grace has a disability! This is not for me... (by then, I wondered whether we just had misunderstood one another!)

- Actually, no I wouldn't say she is disabled.

- Well, you will be then surprised to know that she has been getting the Disability Living Allowance for the past 3 years on the middle rate of the care component!

- Has she?!!

- Yes

- Oh that's completely different then, I will be happy to write the referral letter for you straight away. Good bye...”

I don't think it is necessary to describe how furious, raging and outraged I was as I left the health centre. How could he not know she gets the DLA, how could he tell me there is basically nothing wrong with her and she hasn't got a condition and how could he be 'happy' to change his mind that quickly?! Unbelievable, don't you think?

- III. Kelly has been having re-current chest problems since last November. They said it was a really bad chest infection and needed to be in on IV fluids and anti-biotics blah blah blah - the usual answer for everything! then in March the same happend again, they x-rayed her and saw that the infection was still there so we were sent home with anti-biotics. This continued for the next couple of months, and she had this horrible cough that always caught the back of her throat which then made her gag and then made her bring up her feeds which then gave the added worry of her aspirating problems. We were going round in a vicious circle and getting no where fast, hitting my head off a huge brick wall. The following month once the anti-b's had finished lo and behold her cough returend, I called short stay and said enough is enough why

is this not leaving her wee body, she has been on meds for months now we want answers! The on-call Respiratory doctor called and said Kelly's own chest doctor was on holiday was there anything they could do to help! I explained the past on-going months & everything that's happened, they didn't want to get involved "in such a complicated, delicate little girl" they would have her own doc phone me when she got back from holiday but in the meantime if it gets worse bring her up to short stay for more meds! Arghhhhhhhhhhh. It was felt that we should be seen by Kelly's doctor instead of been giving more meds - alleluia someone is finally listening. I receive a phone call from a doctor who just wanted to check how Kelly was from her visit the week before. I was told "it was noticed on Kelly's Xray last week that there were huge changes on Kelly's left hand side of her lung and should have been admitted and given IV anti-biotics and fluids" OMG - and it took from last week to now for someone to phone and tell us! Let's just say the complaint is on-going!

- IV. Health I am always worried about. Fortunately my GP has backed me up with I have a right to be stressed and it's never going to decrease. But I do worry it might push me over the edge and worry that I am going to end up with a stroke!!

## Relationships

- I. Hubby out tonight, shame we always socialize separately, must work harder on getting a babysitter...
- II. I never knew that raising the boys on my own would be so difficult but rewarding. They have taught me to become a stronger person, an advocate, more understanding, patient, a fighter and to appreciate everything in life.
- III. I am a strong person. Friends will come to me for support. We all need support. I believe I am blessed in that regard. I have always had a core group of people in my life (most pre-Susan) who I trust completely, who love me good, bad or downright ugly. They are my safe places. In addition over the years, because of Susan being different, I have met people who have literally changed my life, or who I feel I can tell the strangest things to - because they "get it". And those people sustain me, pick me up, dust me off and support me until I get my energy levels back up there.

## Aspirations

- I. I hope in the future to move back home and become semi-self-sufficient, to marry my partner, to spend some time in Orkney, to have my own baby, and to adopt a child with a life limiting, life threatening condition such as Tay Sachs disease, SMA type 1 or a leukodystrophy (though of course I hope more that by the time I am in a position to do this, treatments are found for these diseases!!)
- II. I am sick of fighting the whole year through for my children to be educated, have their potential met and integrated into the society around them.
- III. Every child should win a trophy at some point (for whatever reason) and I am pretty sure there would be less mental health issues on earth. I wish that Grace's skin remains as good as it is now but it would be great if we could reduce the steroids.

The children themselves have also been encouraged to keep a diary of their thoughts and feelings on a range of subjects. Excerpts from these diaries are as follows:

- I. 'One trait of autistic spectrum disorders is having fascinations and fixations. Although I am not synaesthetic (one sense accompanying another, most commonly seeing colours along with hearing sounds), I do imagine different colours for different music. Minor key evokes blues and greens and browns and dirty yellows. Major key evokes bright, primary colours. But really beautiful music is like a rainbow spectrum of colours swirling and merging and blending beautifully, like the aurora borealis in my mind.'
- II. Hi I am Millie, well I will tell you a bit about the past couple of days on my holidays. Well it was a privilege using the wheel chair because we got to go to the front of the line at the airport to put our bags in the conveyor belt. The hard bit was the stairs to the plane because I have two sticks. Holding the bar wasn't that hard but it did go higher and higher, but once on it was pretty easy.

III. I am called Grace and I am four and a half. I live with my family. I love all of them. I like playing in the park with my best friend Serena. I have eczema. It gets me massages on my skin when my Mummy creams me but sometimes it is red and sore. Yesterday, I went to see a French allergy doctor. She wasn't very nice. She gave me lots of injections in my arms and it was sore. But at the end, I got to pick a lollipop and I chose the coke one. It was cheeky because Mummy doesn't let us have coke at home. That made me and Mummy laugh. I am not wearing my bandages today because it is too hot and the doctor said I could try some sun on my skin this week. In ten sleeps, I will start primary school. I am happy because Serena will be in my class and I will have a good time there with her. I will try my best at my homework. At lunch time at school, there will be a teacher looking after me and creaming me.

In the final Diary Project report, due to be published in 2012, we will include a more detailed analysis and discussion of all the data gained over the lifetime of the project.

## 6. Next Steps

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The project will continue to record diaries until December 2011. In the next period we will focus on the following;

- Recruiting a few more participant families. In particular we are trying to recruit families that represent some of the characteristics that we have not managed to cover yet including;
  - Ethnic minority families
  - More families living in rural areas
  - Grandparent carers
  - Families with a child who has had an accident and as a result has become disabled later in their life
- Another event will be arranged in order to induct new participants to the project and to receive feedback from existing participants on their experience of the project so far. This will also allow all the families to meet up and make the connections they value as a key part of the project.
- Participants will be encouraged to talk about specific subjects in their diaries, as suggested by fSDC Liaison Project this may include current news stories on issues for disabled children in Scotland such as funding/cuts to services; new policies; short break services, transition e.g. secondary to higher education or work; accessing childcare facilities in their local area; education issues such as additional support for learning; holidays.
- Promotion of the project will continue through fSDC's html newsletter and website, and through each of their coalition member organisations (currently around 60) who promote the project via their own newsletters and events.
- Continue to use twitter and facebook to promote new blogs as they are published.