



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

DIARY PROJECT

March 2012



Final Report
for Scotland's Disabled Children Liaison Project

Acknowledgements

for Scotland's Disabled Children (fSDC) Liaison Project would like to thank all the participants of the Diary Project for taking part and telling us about their lives.

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Particular thanks also to Donna Tomlin, Policy Assistant for her invaluable contribution in coordinating and promoting the work of the Diary Project, enabling parents, carers and disabled children to have their voices heard.

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

Photographs kindly supplied by the fSDC diary project participants, Indigo Project Solutions Ltd, Donaldsons School and W. Rutherglen.



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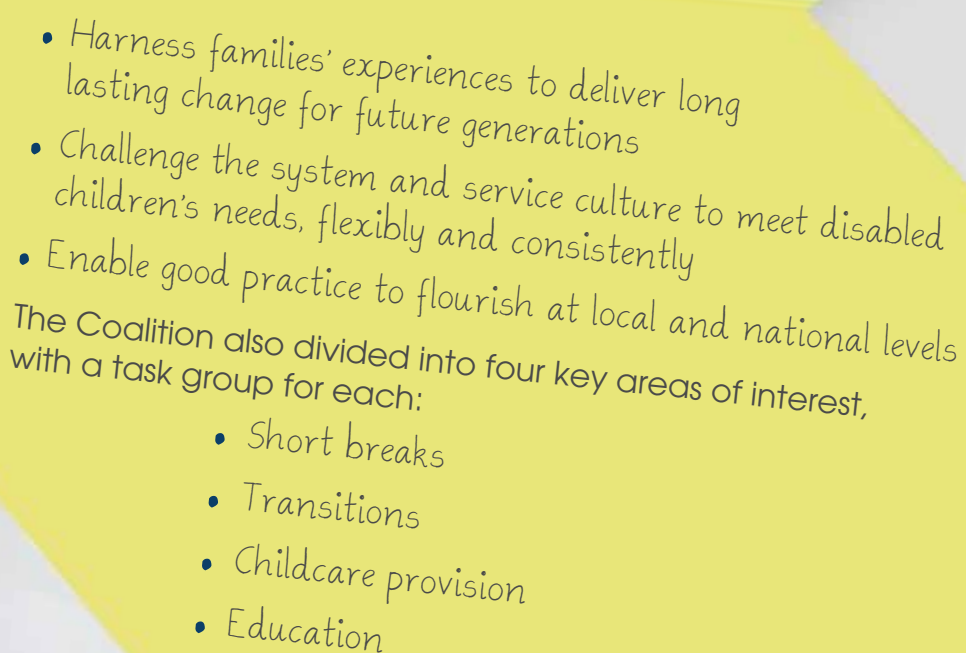
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1. Background to the Diary Project

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
- The Coalition also divided into four key areas of interest, with a task group for each:
- Short breaks
 - Transitions
 - Childcare provision
 - Education

Consequently, the fSDC campaign gained 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".

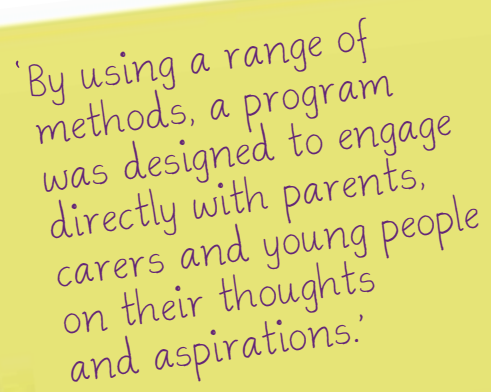
Work on the Liaison Project commenced in February 2009 and was hosted by Contact a Family Scotland, with appointments being made for two posts by June 2009. The work was funded for three years. The Project aimed to facilitate areas of work coming under the fSDC banner, but with a focus on carrying out 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.

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The project would 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.

Families told fSDC that they wished things could be different – but what does different look like? How do we promote “different” to the agencies and professionals involved and then work in partnership to make it a reality? If they had a blank sheet of paper and could design a social care system that provided the right support for their child (and their family) at the right time – what would that look like?



'By using a range of methods, a program was designed to engage directly with parents, carers and young people on their thoughts and aspirations.'



One of the innovative ways used to engage families so that they are central to the ongoing process of change was the fSDC Diary Project. The Diary Project enabled parents and family members to share their experiences of being part of a disabled family and to voice not just the issues and frustrations they encountered when trying to access services and support but also to tell us about what has worked for them and their hopes for the future. Using a range of methods including blog, visual diaries, audio diaries, written testaments, the project detailed family life and provided the opportunity for young disabled people to convey their experiences about growing up in Scotland today.

For Scotland's Disabled Children Liaison Project engaged with many "hidden" families from a wide range of backgrounds and geographical areas across Scotland to help give them a voice. The range of families included, lone parents, foster carers, blended families and kinship carers. The diary findings will be shared with key decision makers in Scottish Government, at both local and central level.

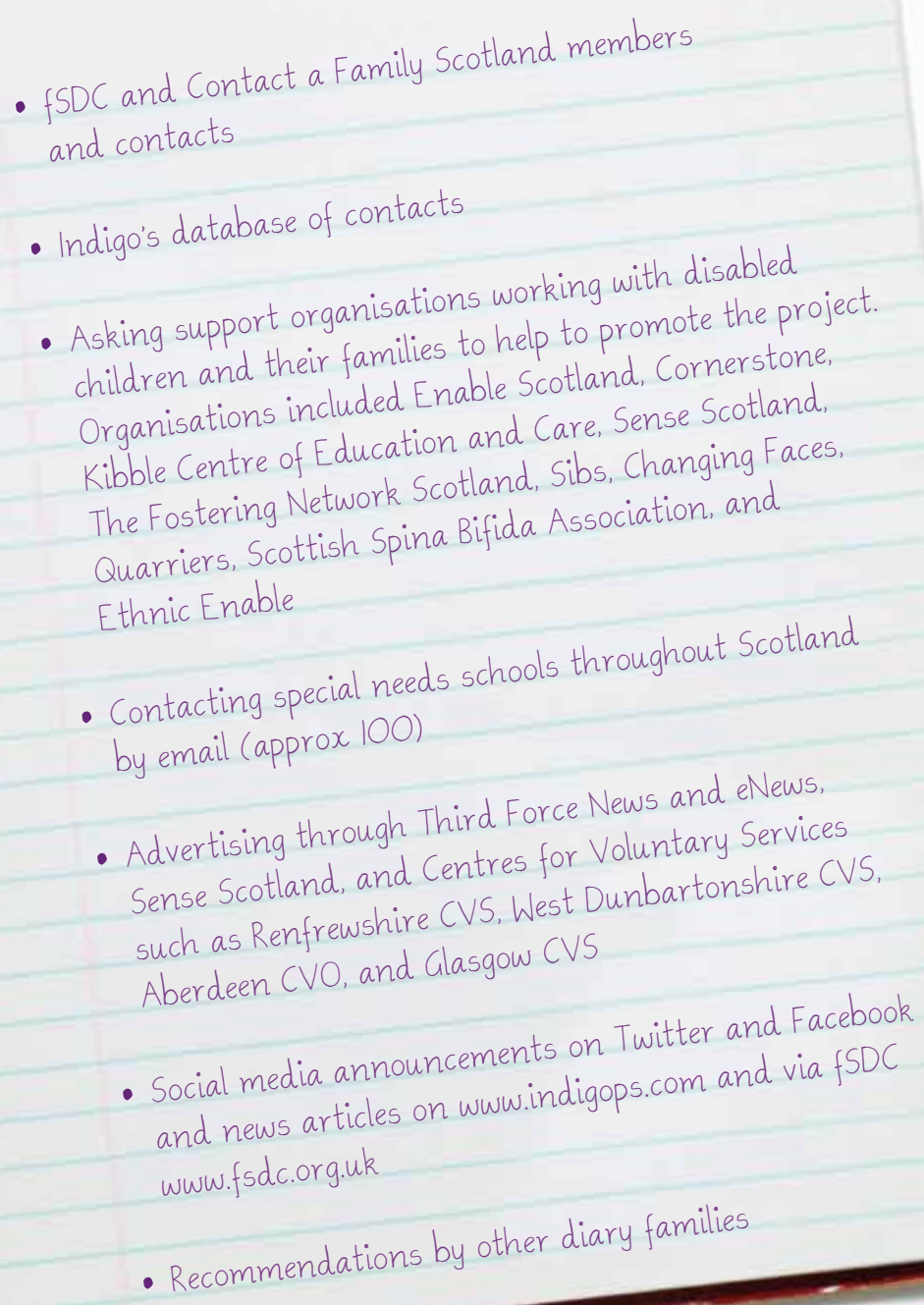
The fSDC Liaison Project recruited Indigo Project Solutions Ltd, to manage the project on a daily basis. Indigo delivered a variety of services including, training, mentoring and supporting participants to ensure the project objectives were met.

More information about the online blogs can be found at:
www.fsd.org.uk/blogs

2. Recruitment and Induction of Families

Recruitment for the project started in April 2010 and continued throughout the project lifetime. The first participants started keeping their diaries in July 2010.

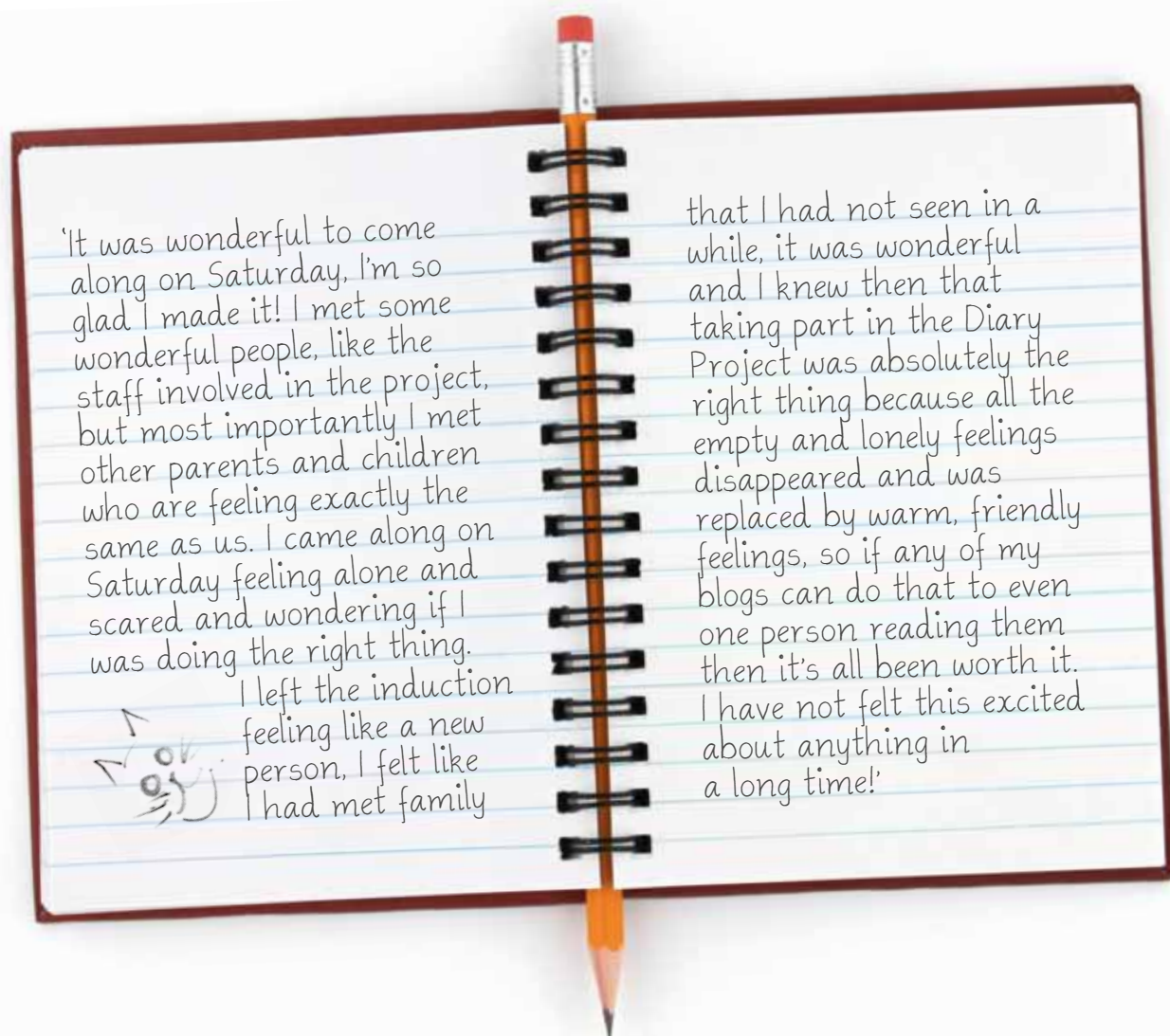
Participants were recruited from a range of organisations and sources including:

- 
- fSDC and Contact a Family Scotland members and contacts
 - Indigo's database of contacts
 - Asking support organisations working with disabled children and their families to help to promote the project. Organisations included Enable Scotland, Cornerstone, Kibble Centre of Education and Care, Sense Scotland, The Fostering Network Scotland, Sibbs, 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 and via fSDC www.fsd.org.uk
 - Recommendations by other diary families

3. Events

As previously detailed in the fSDC Interim Diary Project Report (published by the Liaison Project in 2011)¹ an induction meeting for participants was held in August 2010 at Donaldson's School in Linlithgow. The event 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 for the equipment and software required to record their diaries. 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.

A mother commented:



1. to access report go to www.fsd.org.uk/assets/files/fsdcinterimreport.pdf

A second get together was held at Donaldson's School in May 2011. The aim of this meeting was to induct new families and also to discuss the future of the project with all of the participants and plan what the next stages should be. A highlight of the event was a presentation and workshop by Colin Young entitled Universal Rights for Disabled Children and their Families. The event ended with a dance performance from Marion Sweeney School of Dance which was both demonstrative and participative which the children and adults enjoyed. Specialist childcare was again provided to ensure all family members could come along.



Marion Sweeney School of Dance

Specific group discussions at the event looked at potential themes for diary topics in the future. These included:

- Achieving independence for family members
- Legal guardianship
- DLA renewals
- Direct Payments

4. Family Characteristics

As a result of the recruitment process we spoke to more than 30 families, however only 16 have been able to commit time to the project. It has become clear throughout the project that time is the highest commodity for families with disabled children and that there are not enough hours in the day for parents to deal with the additional demands that life brings. The amount of time spent on the diaries has varied and families have had to take breaks from blogging and recording their diaries during the lifetime of the project to prioritise the care of their children.

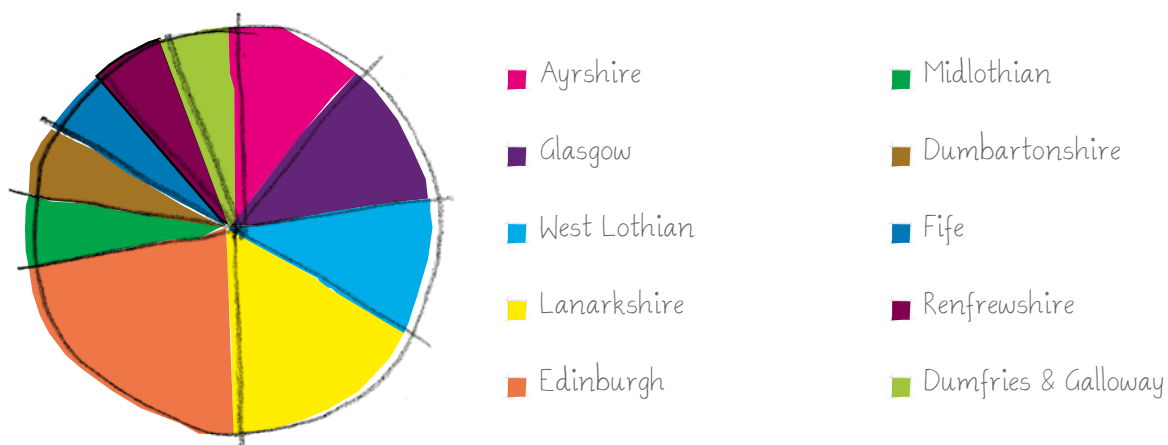


A wide range of families with children and young people were recruited representing a variety of conditions and needs, and living in different geographical areas across Scotland.

Geographical Location of Families

We recruited families from across Scotland and achieved a good cross-section of participants in terms of geographical locations, encompassing the following local authority areas:

Pie Chart showing Local Authority Areas of participating families



Condition

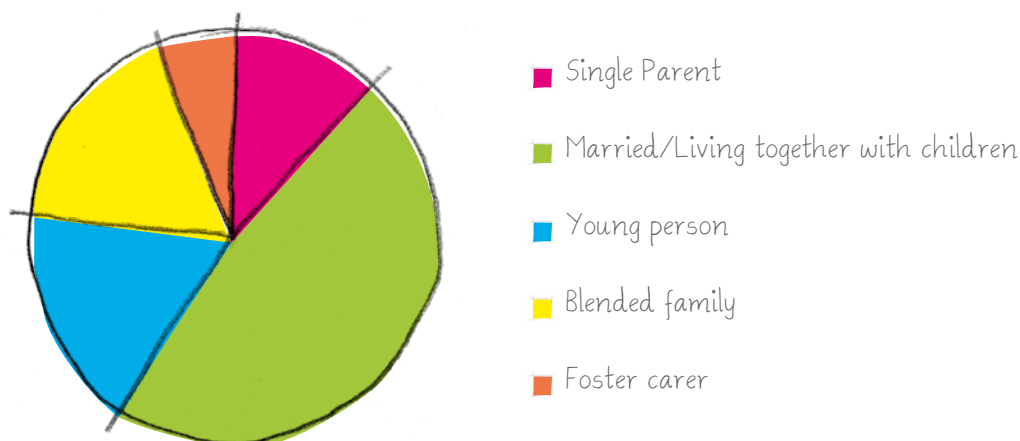
Families recruited to the project cared for children and/or young people with a wide variety of conditions. In most cases children had more than one diagnosis. Examples of the conditions families were dealing with included:



Family Background

We recruited families from a variety of backgrounds, providing a reflective cross-section of the types of families living in Scotland.

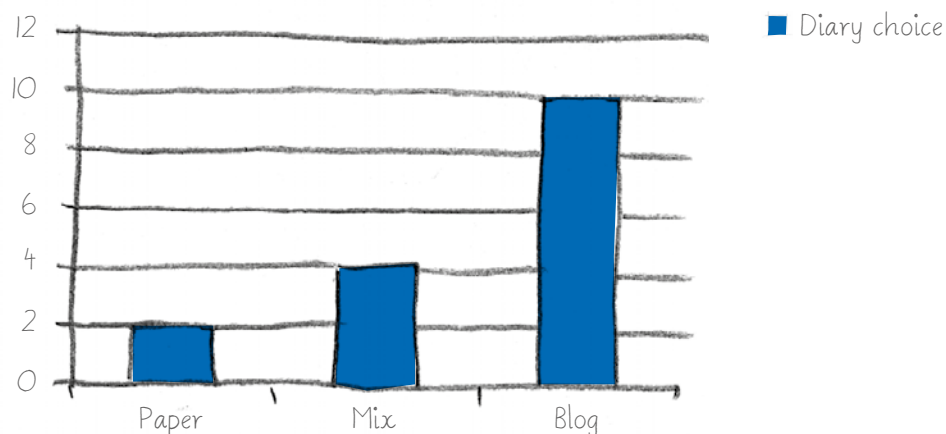
Pie Chart illustrating family backgrounds of participating families



Choice of Diary

Every participant was given a choice of how to keep their diary. Most opted for blogging but the full breakdown is as follows:

Graph showing Diary Choice of participants



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

- 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 future date
- to help change government policy and to encourage improvements for the future
- to make connections with other families.

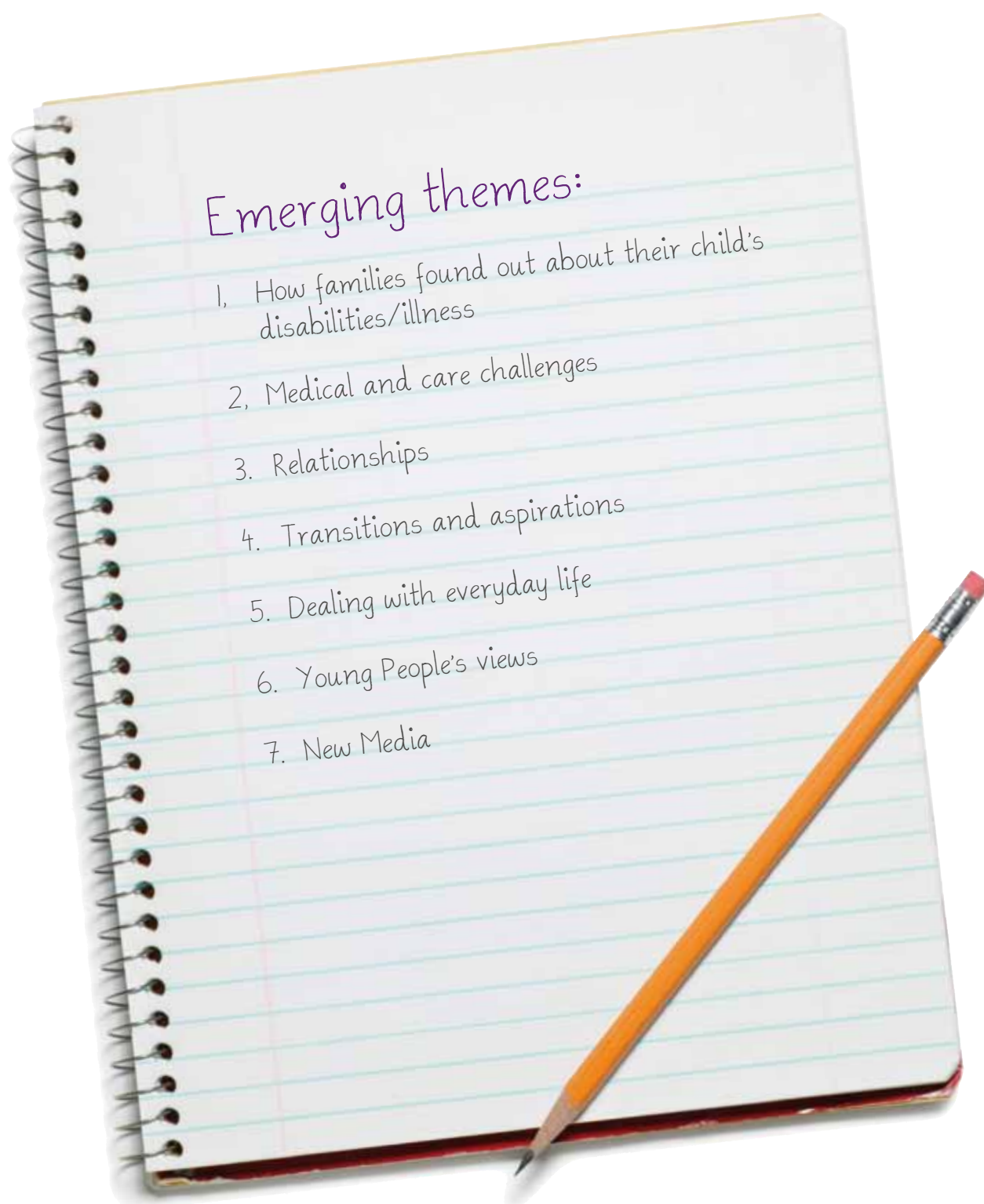




5. Emerging Themes of Diaries

The diaries were monitored and a number of recurrent themes came to light. There are many entries on other themes but the following have attracted most comment so far.

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



Emerging themes:

1. How families found out about their child's disabilities/illness
2. Medical and care challenges
3. Relationships
4. Transitions and aspirations
5. Dealing with everyday life
6. Young People's views
7. New Media

Theme 1

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

This was a very important and emotional time for families and many started writing their diaries at this point. The majority of respondents found out about their child's disability at birth. As to the nature of the disability, this was not determined until the child started to develop over the months and early years. Adjusting to this news, as well as the experience of having a child and trying to learn and understand how to care for a baby/child in a general sense was sometimes overwhelming.

All participants communicated that from the outset it was 'a real roller-coaster ride' of emotions. Once diagnosis had been confirmed, dealing with and managing the disability was, on occasion, distressing.

Diary Excerpts:

After a week a Dr came to me and told me that my son had Noonan Syndrome. He had two holes in his heart, his liver measured 6cms when it shouldn't have measured anything and his kidney was enlarged and he wasn't producing enough urine. I was told that he would need to have heart surgery before he was 4yrs old. There was so much to take in and I just couldn't process all the information that had just been passed to me. After getting moved back to our local hospital I was told that the only way that I could get my son home was to learn to replace his NG tube so that I could feed him, I was to love him as they did not think that he would see his 1st Birthday. Well that was 17yrs ago...

'Kiara was born 16 weeks premature in 1992. She was in hospital for nearly 5 months which was a real roller-coaster ride for all of us, especially for her. We knew there was some problem with her eyes but it was not confirmed until she was about 6 months old that she was in fact totally blind... she had had a brain haemorrhage on day 2 and we had been warned that this could result in brain damage.



'My name is Denise and I am mum to the incredible Selena. Selena is a fabulous, bolshie, shimmy-shammying fourteen year old. She is also different. Shortly after her birth she was diagnosed with a rare chromosome disorder, Ring 18. Selena also has an Autistic Spectrum Disorder.'

'Mouse has complex needs, cerebral palsy, developmental delay, no speech, fluids via a mini button – though she eats a modified diet. She has an allergy to cashew and pistachio nuts. She is able to communicate a little by expression, touch, sometimes by looking, and big mac switch. Mouse is unable to walk or stand, over the last year she has managed to achieve better sitting balance and has learned how to bum shuffle about the house. We have always tried to help stimulate her to reach her potential and like to source the most suitable but not too expensive equipment to enhance our live, but without our home being overloaded with too many pieces of equipment. We have been lucky that our views have been taken into account – nearly always up to now.'

Mouse has had good input from the physio S.A.L.T and as a 2 year old was able to start attending the local school for children with profound difficulties on a part time basis, like nursery. The school she attends is very small and has been great for her – being encouraged by staff who know how to help her progress, and who encompass the whole family in her learning experience. We have been lucky that Mouse keeps quite good health with only a few short stays in hospital over the years.'

Theme 2

Medical and care challenges

This theme appears often and is the issue that concerns parents and participants the most. A number of respondents highlighted the difficulties in securing financial assistance for various needs and to get the right equipment and adaptations when appropriate. Changes in provision of services were also highlighted. This included the regular supply of nappies and bandages suddenly being stopped or frequency of supplies changing leaving the respondent to contact the health authority to request the missing supplies. Little or no communication was received regarding such changes of service provision.

All diarists highlighted the length of waiting time to secure medical appointments and delays in accessing medical tests and the subsequent wait for a diagnosis. It could take a long time for decisions to be made and in some cases letters from consultants were required in order to obtain a response from other professionals.

Diarist also highlighted a lack of joined up thinking in their experiences of dealing with the array of services they were coming into contact with. A lack of clarity was identified around issues such as legal requirements for people travelling in wheelchairs. Advice on adaptations which needed to be made to the home was also inconsistent and confusing, highlighting a lack of understanding around the needs of the child with a specific disability.

All diarists reported on the long hours being worked to provide care for their child. One commented that they exceeded 100 hours a week providing care support – exceeding the working time directive. Short Breaks were noted with one participant stating 'it's not law, its luck' if respite/short breaks were received. Other comments included 'There is no government support in terms of sickness cover for families of disabled children...' and that it is a 'full time job'.

Diary Excerpts:

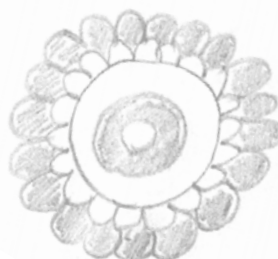
'I thought I'd update you about our occupational therapy application for some financial help towards an adapted shower for Grace (power shower). (see previous blogs). After months of waiting... I got a phone call last week saying: 'we can't do anything for you, we don't fix 'not ideal situations', only medical and care emergencies'. So that's it, it is the end of the road for some help from them. My mother said she would help us to get that shower for Grace anyway at the week-end. Thanks, mum! She gets it, she understands the need, as opposed to the teams of experts supposed to improve the rights of disabled people and work towards a fairer society...'

'We lived in a one bedroom house when we had the twins, in fact the day we got our IVF results (7/7/6) was the day we got the keys to our house, as we were totally convinced that the ivf wouldn't work again! So just after the twins first birthday, we couldn't live in the cramped house any longer, by now Rachel had a tumble form chair, a monkey standing frame – plus we had Rosie's moses basket, & bouncy chair – We didn't need the other one... Rachel had her wee special seat. We saw a 2 bedroom house, which was still in our wee village – cut a long story short, we sold the house we were in and bought the other one. Once we had done all the work that was needed and had moved in and got settled, the social work occupational therapist came out to asses the house. The report reads "Rachel needs a ramp, a stairlift, a bath aid, a downstairs toilet and sleeping area – the house is not suitable for Rachel unless the adaptations are carried out. But as the family owns their home they are not entitled to help from the council as they are homeowners. Excuseeee me, what does this mean?? Yes, I had read right, Rachel gets penalised or discriminated against because her parents pay a mortgage and not rent! What is the difference – since when did our kids start being means tested! I took it further, I complained, I lost the plot and the will to live as no one could answer why Rachel was not allowed any help that was needed just because we owned our house. I asked for a council house, but we weren't on the list and they didn't have any anyway. What else can I do? I was then told from the sw o/t department to take it up with the government, and that's exactly what I did! That ladies & gentleman, is what spurred me on to the campaigning I do – the fight then starts in my next blog!'

BLOG
Comment

'Due to Mouse being a looked after and accommodated child it is very difficult to fund raise to help buy her wheelchair or any other expensive equipment ... Fought the battle to see if we could get funding for her wheelchair from wheelchair services or social services – still no joy – and I'm not willing to put Mouse at risk ...'

'Expecting delivery soon of wheelchair only to find out there had been a mix up and the wrong size was ordered, so now having to start the wait again for the correct size. Disappointing, but not the end of the world. Everyone can make a mistake, lucky it wasn't our mistake as chairs made up to order!!...'



'On the health scene, Carl has been referred to hospital for an ultra sound as the Dr seems to think that all his tummy issues and pain is coming from his gallbladder. He is still waiting on an appointment for the orthopedic surgeon to see about his elbows which can't straighten. Our GP thinks that this has happened because when he was about 14 years old he was given growth hormone treatment for about a year and it was the side effect of that. What's the NHS coming to? Carl still hasn't been started on the Concerta for his ADHD. CAMHS don't even return calls as we have been trying to set up a meeting with the psychiatrist and pharmacist to get him started on the drug before he starts college. Hard to believe that he has been waiting since he was diagnosed in January.'

Theme 3

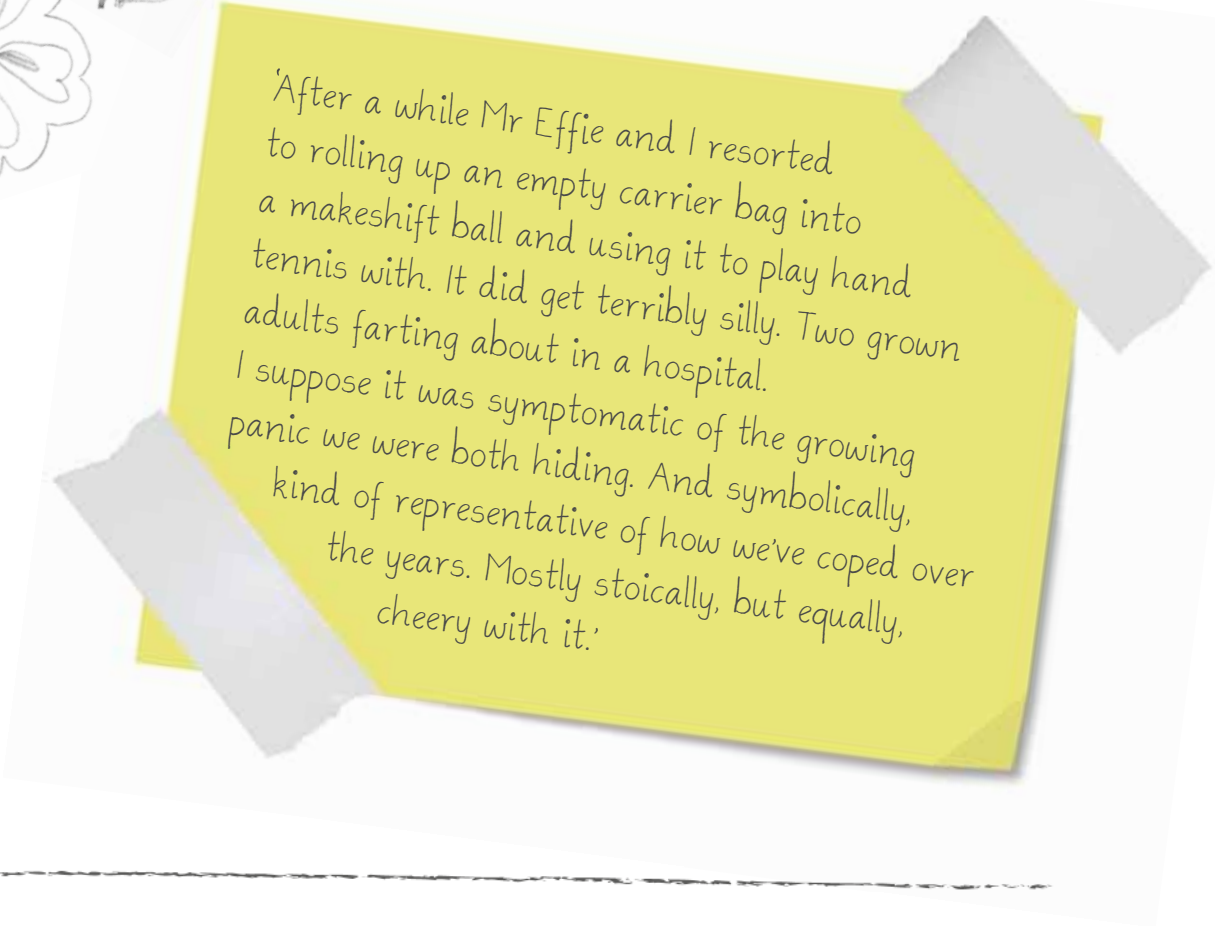
Relationships with extended family members

All diarists highlighted the importance of extended family members in providing emotional and short break support. Despite the tiredness and frustrations, all participants have adjusted to their change in circumstances. The problem for some was that the only support they received was from friends and family and felt that nothing else was available.

Diary Excerpts:

'Grace and my grand-daughter are good friends and often play together. She has a very positive attitude and is a polite, spirited and helpful 5 year-old girl. I have never heard her complain about her painful eczema symptoms even though I know that she is going through a lot of discomfort, often battling against infections and allergic reactions.'

'Family gathering on new year's day. Busy house but really enjoyable. Mouse happy and shows off her progress to family members she doesn't see too often. Our new granddaughter born, up north, so had a few days holiday to see her. Mouse liked the baby and the dog they have. Really funny to watch her relating to them and being interested. Coped well in strange bed and diet, etc, ok as we take the food chopper and feed tubes and bottle warmer to heat evening milk.'



'After a while Mr Effie and I resorted to rolling up an empty carrier bag into a makeshift ball and using it to play hand tennis with. It did get terribly silly. Two grown adults farting about in a hospital. I suppose it was symptomatic of the growing panic we were both hiding. And symbolically, kind of representative of how we've coped over the years. Mostly stoically, but equally, cheery with it.'

'On a good note Carl has finished all his exams and will graduate High School on the 13th June. His celebration will have to wait until the following weekend as I am off to Aviemore for a carer's conference that weekend. Time for me to relax and recharge my batteries. My mum and dad will be keeping an eye on the boys while I'm away so that there will be no wild parties...'

Theme 4

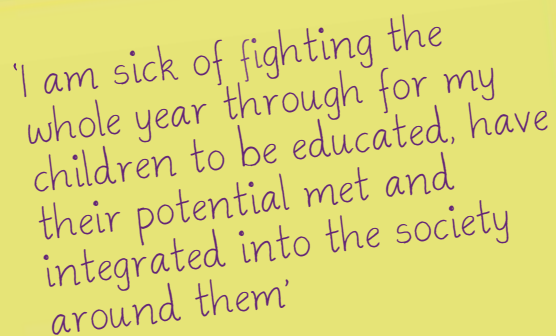
Transitions and Aspirations

A number of respondents mentioned that there was conflicting information from social workers and education authorities. In some cases they suggested solutions and then nothing further was heard. This was especially evident when young people were about to leave school, a point of transition which was highlighted as causing a particular set of concerns.

Positive stories included those of a diarist wanting to go to university to study for a degree in creative writing whilst another has managed to secure voluntary work as well as waiting to hear about paid employment in a garden centre and college courses.

Diary Excerpts:

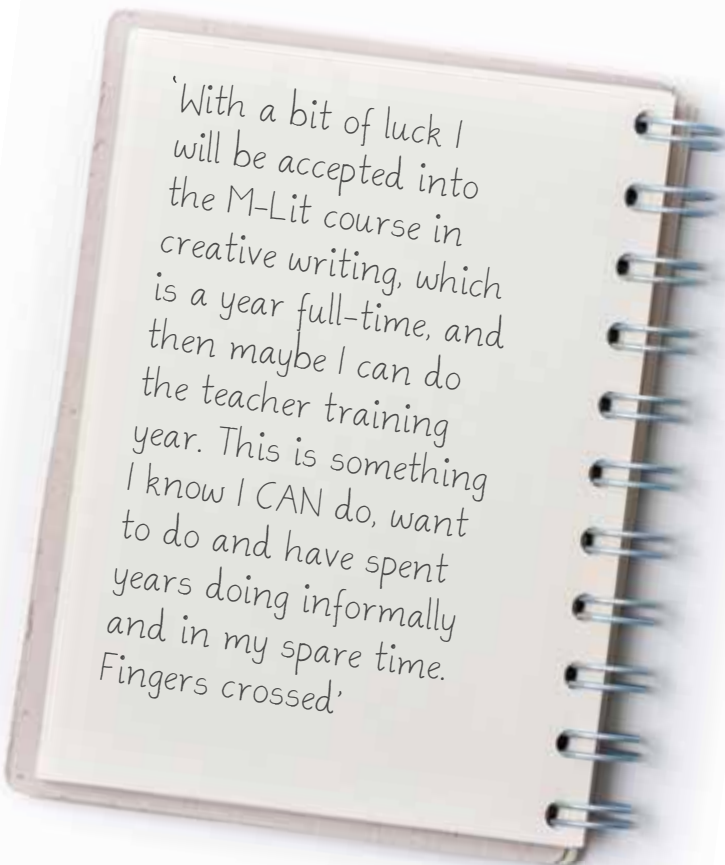
'...We have had good support from school staff, a transition worker and various other professionals who have attended transition meetings. It appeared that everyone was in agreement with us at a recent transition meeting that the package we preferred would best meet her needs. However our local authority's resource allocation group (who do not attend review meetings) has thrown a spanner in the works by suggesting just two weeks ago that our social worker should look at a service we have never heard of to see if it meets Kiera's needs. Why were we never told about this before?'



'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'



'The Education system let him down big time. I not only had to fight for three years to get his Record of Needs and IEP but I always had to be on their backs to make sure that they supported Connor when it was needed. There were times when I was ready to pull him from the school just to make life easier but me being me dug my heels in and made sure that Connor got a education that he deserved...'



'With a bit of luck I will be accepted into the M-Lit course in creative writing, which is a year full-time, and then maybe I can do the teacher training year. This is something I know I CAN do, want to do and have spent years doing informally and in my spare time. Fingers crossed'

'Now that my son is at college what a difference, the support is all in place and he also got a brand new laptop. At least I can relax with his education and career. He loves college and has settled in well.'

BLOG
Comment

'Hi, this is a great inspiration. My baby girl has eczema from 2 weeks old and I've been inspired to start a blog for stressed out parents with eczema children, to create a childrens book to encourage eczema kids not to scratch.'

Theme 5

Dealing with everyday Life

Over the winter of 2010/11 large amounts of snow fell in Scotland affecting the lives of many of the participants of the diary project and creating significant challenges to daily life. Simple things such as roads not being gritted created insurmountable problems for many and the difficulty in getting out became more apparent. Many diarists managed to gain a sense of normality around Christmas time with parents being able to attend festive shows and social events.

A number of diarists are trying to raise awareness of their own or their child's disability and to share that information with other families who perhaps are in a similar situation.

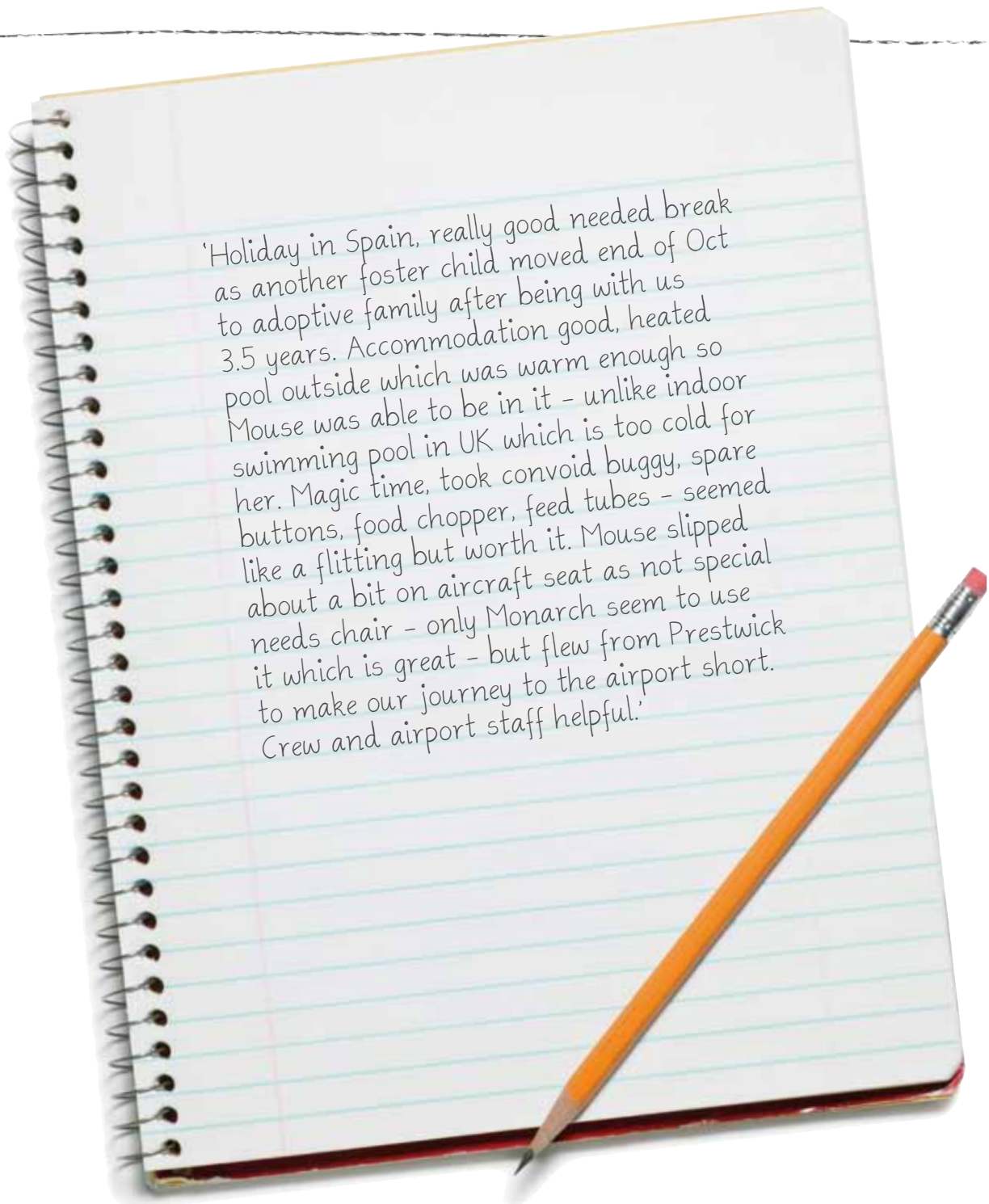
Diary Excerpts:

'The boys have been off school for 2 weeks now, due to the ridiculous amounts of snow we have had and the inability of the council to grit the roads and paths at the schools to enable them to get there. J's school bus got stuck going up the hill to his school on Monday so thank goodness I refused to let him go on it after a friend told me the roads in that area were lethal. What I can't understand is if a friend can drive there and say it is too dangerous, why did the risk assessment by the school not say that?'

'T is much more sensitive and suffering more from cabin fever, although he said this morning that he does not want to go outside just now - 'too cold' as he is very sensitive to extreme temperatures due to his severe sensory problems.'

'We all had a lovely time at Christmas and new year. Mouse seems to enjoy herself but it's often hard to know what she thinks/feels. It's so easy to see the toddlers' excitement but we've always just hoped that her smiles and interest lets us know she's enjoying herself.'

'(T) is getting bored and more introverted, twiddling with his belt and daydreaming constantly... J is better at occupying himself with his drawings and writing letters. I am amazed how well he is doing learning to write, after having a severely dyspraxic child (T), it is astonishing to have one who wants to and can, write! It is all the more amazing because he has a severe speech delay and limited understanding, but he just wrote Christmas cards to all his class mates with correct spelling and forming all the letters perfectly.'



Theme 6

Young Peoples' Views

The younger participants voiced their views by blogging and detailed their social interests and experiences in trying to lead as independent a life as possible.

Diary Excerpts:

'...I have Cerebral Palsy and use a wheelchair. I have been living in my own flat for a few years now. I spend most of my time volunteering, playing sports and listening to music. I currently run a project called Different Shot it is a photography project looking at what the world is like when you having a disability...'

'As for the course itself - I'm still struggling a little to make friends as I find the stepping-round-each-other-on-eggshells bit difficult. This is one of the things I love about acting. You are thrown together with like-minded people, and you have very little time and a great need to become close quickly - it bypasses all that awkward first stage out of necessity.'

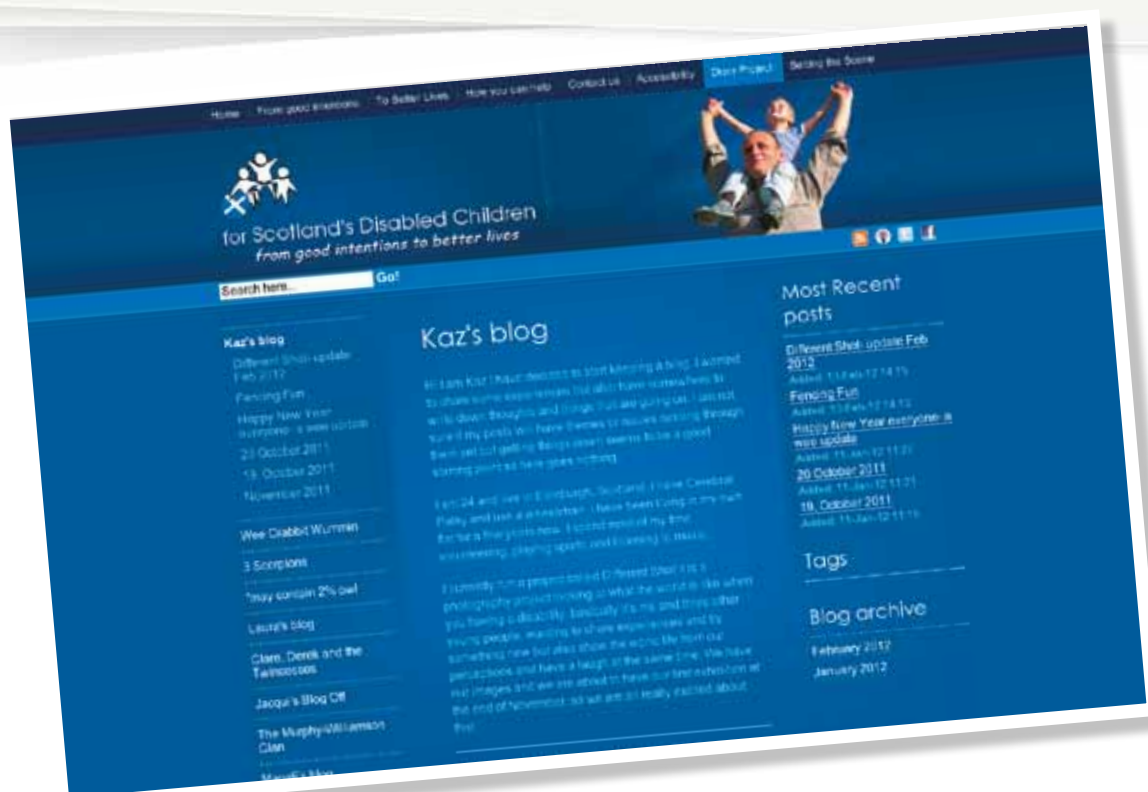
'After our seminar, the facilitator invited the class down to the pub. I don't fair well in pubs, as I can't drink and don't much like close crowds, so I decided to go back home. And I joined force with the only other two people heading in the opposite direction from the main crowd! Both of them found social interaction somewhat difficult, so when we found that in common, paradoxically we all relaxed!...'

'People would be surprised to know: That something as simple as getting stressed out can raise your internal levels of branched chain amino acids (the components of protein that are so poisonous to me), because you use up all your stored energy stressing and have to resort to breaking down your own muscle protein'

Theme 7

Social media

Using social media was an important advantage for people to communicate and share their experiences. The internet has enabled diarists to contact other families with similar experiences and share their thoughts and ideas by using social media such as Facebook and Twitter. Many found friends through the diary project and by networking on-line. These new relationships and connections often provided extended support and a 'listening ear' when most needed.



Diary Excerpts:

'There are those who have no time for social networks, be they Facebook or forums... they can provide an incredible opportunity for people to learn, to share and to support each other. Those who have read my other blogs know that I am very honest about the stresses of raising a child who is different, and about depression. I talk often about support and how we all need it and should seek it...'

'This may not make any sense to a lot of people, as it's riddled with blog and IM jargon, but I need somewhere to explode in frustration and confusion, and rant about Asperger syndrome and Aspergian angst...'

'In these difficult times, more than ever we need to keep fighting, keep blogging, sharing, supporting and standing with each other. Sometimes we will be too tired to fight, and that's the beauty of friends who support you, understand you and stand with you, at those times we will fight for each other.'

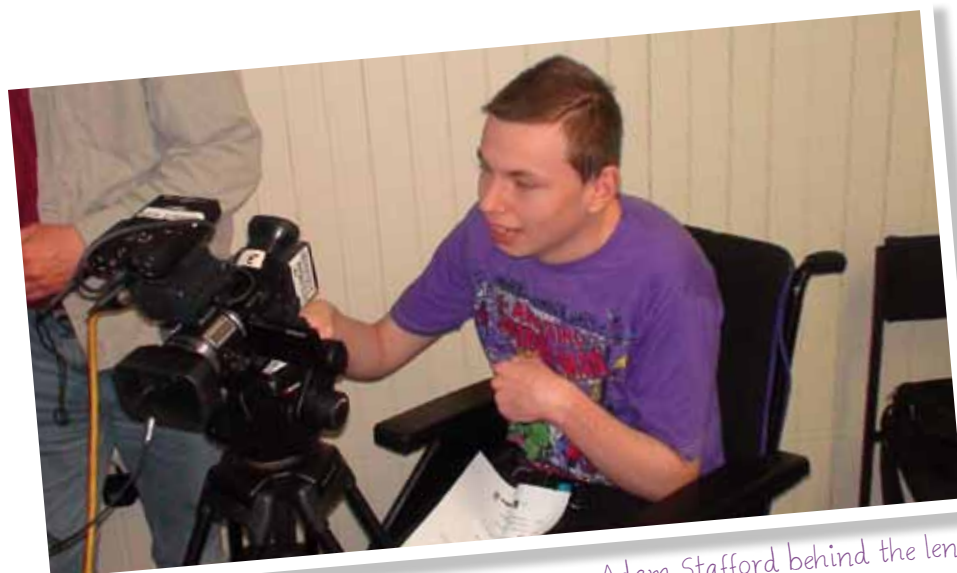
BLOG
Comment

'What an uplifting blog! Uplifting? Yes it was. You wrote exactly how I and I'm sure many parents feel. We're on a roller coaster ride and some days life feels so good, we can cope with everything and on other days, the roller coaster crashes and we wonder how we will go on and we start to think and worry about the future. It is so good to feel how others feel and to know that we are not alone.'



6. Diary Project – DVD

The fSDC Liaison Project worked with a few of the diary participants in January and February 2012 to produce a short DVD to highlight the merits of blogging and to complement this report. The DVD was inspired by some of the younger bloggers who met to discuss the potential benefits of producing a film. Subsequently they took the lead in designing the content and presenting some of the bloggers' stories – bringing to life the issues and highlights from the project. The DVD was produced in partnership with Perth and District YMCA. Both the YMCA young members and the bloggers worked together with a professional television producer, Sandy Raffan, who kindly offered her time and skills on a voluntary basis to support the filming. The team carried out the filming in Glasgow, Perth and Edinburgh at various locations including the SCVO offices at Mansfield Traquair Centre, Salle Holyrood Fencing Club at Holyrood High School and Glasgow University.

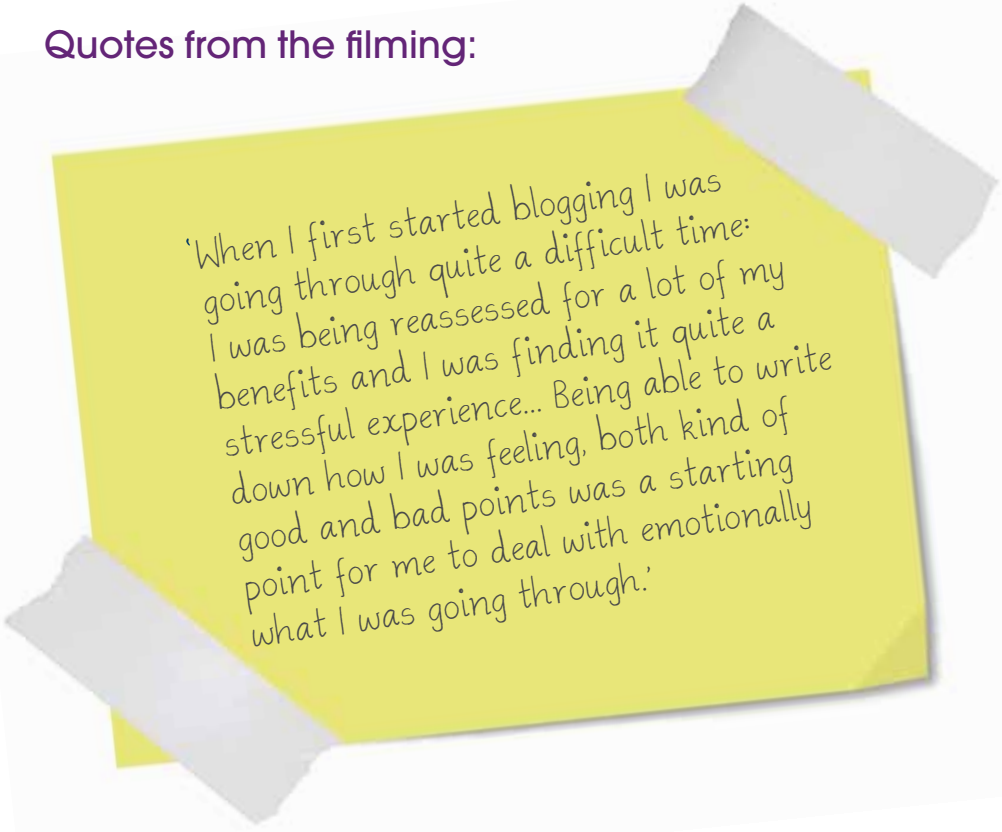


Adam Stafford behind the lens

The diary bloggers compiled their own list of interview questions which included:

- What motivated you to take part in the diary project?
- Why is the diary project important?
- Has using new media (blogging), to voice your concerns and share stories, been a positive experience?
- Is there one thing in particular the government could do to help your family?

Quotes from the filming:



'When I first started blogging I was going through quite a difficult time: I was being reassessed for a lot of my benefits and I was finding it quite a stressful experience... Being able to write down how I was feeling, both kind of good and bad points was a starting point for me to deal with emotionally what I was going through.'

'I was motivated to take part in the diary project because I wanted other parent carers to know they weren't alone. There's nothing worse than feeling lonely.'

'Mainstream sport is very important but don't forget about disabled people. 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.'

'The good thing is that when you are writing about your life, you think about your experiences and the services you're using a bit more thoroughly. So in a way it is a reflection of your life, it tells you a lot about yourself – a bit like therapy!'

'I would like to see in the next few years the government supporting the third sector in the way of partnership working with the NHS and schools, for example and better sustained funding for charities.'

The DVD is presented by Laura Guthrie, with additional editorial content by Adam Stafford – two of the diary project bloggers. Two families and another young blogger also took part in the filming and the DVD is available to view on www.fsdco.co.uk/blogs

7. Future Initiatives and Next Steps

The current phase of the Diary Project ends in March 2012. It is hoped that a second phase will begin later in the year with an opportunity for existing participants to continue and new diarists becoming involved.

At the May 2011 event, the diary excerpts were collated and a number of key discussions took place with the participants in regard to what initiatives they would like to take forward if the project were to be funded past March 2012.

Suggestions included:

Initiative 1 – Helping Others

There are a number of common issues which affect participants and families. It was agreed that this experience and knowledge could be more widely shared in the form of tips and guidance to help other parents and carers. It could be collated in the form of a database holding specific information on types of equipment, suppliers, resources and additional (non local authority) services available in their local area. The information could be shared on-line, freely available to other families and be used as an additional resource by professionals and support organisations.

Parents and young people felt it would provide an opportunity for organisations to promote second hand resources and recycled equipment for families and children. From current discussions with some of the diary participants there is a severe shortage of wheelchairs, and if there was an opportunity to recycle equipment such as this, it would alleviate pressure on local authorities and most importantly those needing the equipment. It was suggested that this facility would potentially become an income stream (via advertising) for the diary project itself.

Initiative 2 – You're Not Alone

Throughout life people confront experiences not realising many others have encountered and overcome similar obstacles in the past. The You're Not Alone initiative is all about sharing that experience to help people realise they are not on their own.

For many diarists, motivation for their participation had come from a desire to extend a supportive voice to others who might be going through similar experiences to their own. New media had proved to be a vital vehicle in enabling and empowering participants of the Diary Project. It had been a particularly important tool for participants experiencing isolation, with benefits such as being able to blog or make connection with people late at night being cited as key in making people feel they were not alone.

Continuing, developing and funding supportive resources such as those which were easily put in place through new media approaches was seen by participants as key to the success of the Diary Project to date.

Initiative 3 – Signposting

'Knowing what to do or where to go for help, or just even where to start has a considerable impact on any family. To support all initiatives it was felt that there is a need for a form of reference manual to explain, at the point of diagnosis and beyond, what they need to know and where to get appropriate assistance. It is fully appreciated that there are a huge range of disabilities and conditions, which would make the manual a large and unwieldy publication. It was suggested

that the publication could be limited in scope and be very generic with general guidance and signposting for specific areas. The possibility of using web technology to provide a fuller online resource for information support on specific conditions could also be developed.'



Initiative 4 – Making Everyone Aware

The participants explored opportunities to publicise the Diary Project focussing on specific audiences and using different methods of communication to explore the many issues faced by families and raise awareness in wider society. Suggestion for ways to do this included:

Exhibition

Highlighting work of the Liaison Project to date and pinpointing key issues.

Events

These could range from small bespoke events in specific communities to parliamentary events for MSP's and key stakeholders involved in making policy. These events would highlight the initiatives and challenges being faced by families and to address these at all levels.

Reaching Decision Makers

A campaign could be designed to communicate a number of issues:

- raise awareness of the savings that families caring for disabled children represent for government
- promote a range of resources for families and stakeholders to use and refer to
- general awareness raising across the political and care spectrum
- the need for a first point of contact for families on all issues affecting them.

Social Media

The project could develop its current reach through the power of social media approaches. This will be supported by a range of methods including:

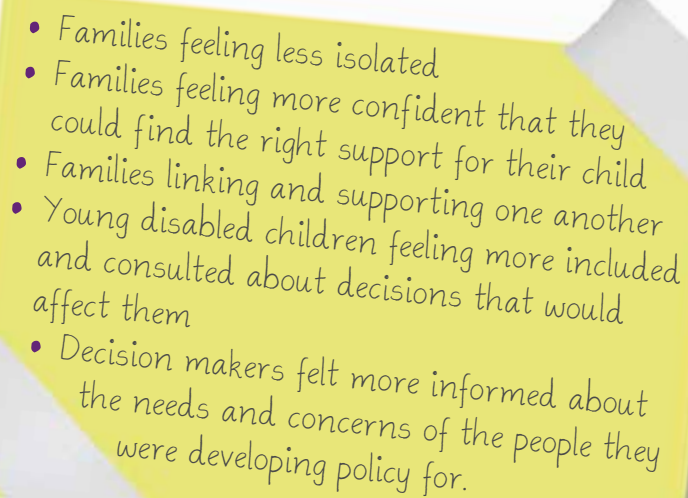
- **Blog**
communicating everything from people's experiences to latest information
- **Facebook**
putting a face to the experiences being conveyed and who was getting involved and why
- **Website**
updated information and references to support families
- **Media**
highlighting issues in local and national media, as well as through innovative approaches such as You Tube.



8. What We Have Learned

In the course of the Diary Project, clear themes have emerged illustrating specific issues that diarists were keen to highlight. The blogs and diaries provide clear examples of the experiences of individuals and really bring to life what a broad change to policy or provision at a national level can really mean for an individual. We have been able to categorise the subjects participants were keen to talk about, providing valuable information to inform developments or changes in different policy areas, and giving decision makers a route to hearing the voices of disabled children, their families and those working alongside them. The project provided accessible avenues for people whose voices have previously been overlooked to feed in their experiences, and new social media was instrumental in facilitating this.

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. All participants had valued experiences of being involved in the Diary Project and were keen to see for Scotland's Disabled Children taking forward a second phase of the work to date, with emphasis on developing the initiatives outlined above. 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.

Whilst many of the outcomes of this work are difficult to measure, the importance of issues like emotional support at times of crisis are seen by the participants as absolutely key to improving the experiences of families supporting disabled children. Ultimately, such preventative measures as these would mean that disabled children are enabled to reach their full potential and have the best start in life as reflected in the Scottish Government's National Performance Framework strategic objectives.

It is hoped that next steps for this valuable area of work would focus in on the suggestions of the participants and take forward work in all of these areas.



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