

News



Down's
Syndrome
Scotland

helping people realise their potential

Shifting Public Perspectives

First time Dad

Hats off to the training team

Making inclusion in school a success



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Disclaimer

Articles in this newsletter reflect the opinions of the contributors. These are not necessarily the views of Down's Syndrome Scotland.

Down's Syndrome Scotland is a partner organisation in the Scottish Consortium for Learning Disabilities (SCLD).

Lou Marsden
Senior Information Worker



Editorial

In 2006 the first World Down's syndrome Day was held on March 21st. This date was chosen by Down's Syndrome International because when written numerically (21.3) it signifies the presence of the additional chromosome on the 21st pair. It is a day when Down's syndrome organisations all over the world raise awareness and celebrate the uniqueness of every individual with Down's syndrome.

2009 marks the 50th anniversary of the publication of Professor Lejeune's discovery of the extra chromosome on the 21st pair. Many advances have been made during this time in the health, education and social care of people with Down's syndrome. More important have been the changes in the expectations and aspirations of people with Down's syndrome to access and enjoy all aspects of what this world has to offer.

We had great feedback about the new look newsletter, particularly how much better the photographs look in colour. Please remember to send in any articles, comments and photos that you would like to share with all our members.

Regards
LOU.

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On the Shifting Perspectives exhibition

Pandora Summerfield
Director



The Director's desk

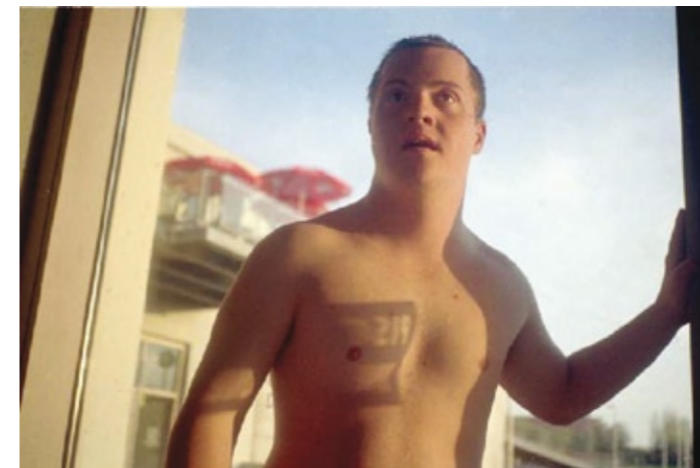
During my meetings with members last year, one of the things that you told me was important to you was to raise the profile of the charity and to raise the awareness of Down's syndrome amongst the general public. On the face of it, it sounds so easy, but we're in a crowded "market place" of charities and competing to raise awareness and profile next to the big charities with large advertising budgets. Nevertheless, our rebranding has given us a boost, with many people (including funders) commenting on the modern fresh image of the charity.

In terms of raising awareness of Down's syndrome, this is the challenge of communicating with a public that generally isn't interested unless they are directly affected. Despite this, we've not done badly for press coverage. We've ensured that we've taken up every opportunity to respond to journalists asking for a comment on a particular issue that they've been running a piece on. Consequently, we've had comments and a name check in a wide range of newspapers on subjects such as birth numbers, screening and testing and most recently on teaching methods for children. In future, we want to be more proactive about media coverage and will be working to find the issues and the angles that will stimulate media interest in our cause.

This is all good stuff, but as someone once said – "A picture paints a thousand words" and so I'm delighted that we have been able to secure the showing of the Shifting Perspectives photography exhibition in order to celebrate World Down's Syndrome Day on 21st March. Jackie Baillie MSP, convenor of the Cross Party Group on Learning Disability will be launching the exhibition and I'm hopeful that there will be a lot of media interest. You can read more about the exhibition later in this newsletter. You'll also see that the Filmhouse in Edinburgh will be screening the feature length version of a film called Heavy Load on World Down's Syndrome Day. Heavy Load are a punk band, three of their number have a learning disability and their drummer Michael has Down's syndrome. This film follows their highs and lows – including a brush with none other than Kylie herself. Don't miss this truly inspiring film which left a smile on my face for a long while.

'Hope to see you there...

Pandora.





The Wee Man

by Ken Charleson
Parent member, Crieff

It began with a scream, then another and then another which seemed to keep going even as I woke up. The warm wind circling the mountain-top hospital gently swept the net curtains back and forth across the open window.

I pushed back the cover on my camp bed. I could see my wife still asleep on her mosquito netted cot, her arm still attached to the saline drip by her bedside. Another scream, short and sharp, this time clearly outside and this time followed by the shrill chattering of the ring-tails swinging energetically from branch to branch amongst the dense foliage of the tangled trees. I wasn't surprised she was still asleep. She had just spent the last 24 hours giving birth to our first child, David.

Slowly but surely, the events of the last day began to swim through my mind like the ice waters of a snow-melted Scottish river, bringing the events of the previous day sharply into focus. Except this time it wasn't Scotland, it was Brazil and the balmy air swirling Corcovado did little to warm the cold dawn of awareness in my fuddled brain.

We had known that Gillian was pregnant before we were posted to Rio de Janeiro and although it meant some adjustment to our domestic routine, basically we carried on as any couple does. It had been a funny thing for me, even though I could see this wee shape moving

around in the grey-black screen of the ultra scan, and I could see the doctor moving the scanner back and forth across Gillian's swollen belly, I couldn't quite make the leap of imagination needed to hold that wee shape in my arms and call it David.

For women it must be completely different. Every day you wake up with this child kicking around inside you. It never lets you forget it's there. And every month you watch yourself getting bigger and bigger and feel it get heavier and heavier and although you still can't hold it, it's there inside you, a part of you as much as your own beating heart or moving arms and legs.

From the start we had decided not to know the baby's sex. We always just referred to it as 'Tosh'. We had also decided against the invasive techniques designed to determine any irregularities in the baby's make up. It was a conscious decision. We talked about it long and hard; the risks associated with the tests, the dilemma that would arise if they found something wrong. How would we react? What would we do?

The decision hadn't been very hard. We would carry it through whatever happened. After all, there had been no history of Down's syndrome in either of our families. Genetically, we were in the clear. Tosh would simply pop out on time and we would all carry on as planned.

“He was the most beautiful baby I had ever seen.”

We quickly developed our new routines in Rio. The city is a dream-like affair, settled amongst the coves of Guanamara bay and dissected by mountains, of which the towering peak of Corcovado with its statue of Christ is the most imposing. A giant Christ, arms outstretched, faces out across the gaping Atlantic to Europe from whence had come the Portuguese who had conquered this vast, still largely unfettered land and who had settled it with Catholicism and black slaves.

We lived well, a luxury apartment with a live-in maid (black of course), about two blocks away from the Ipanema beach. Here, the cafes, restaurants, clubs and bars are open for most of the night. Rio doesn't sleep. They say that every Friday night there is a revolution in Rio, but it's always over by Saturday morning. They also say that there are three religions in Brazil; white catholic, black catholic and football. In Rio there is a fourth, the beach. Just so you understand the beach is where everybody and I do mean everybody, hangs out. The only thing you take to the beach is a towel. Some people don't even do that. Anything else will get nicked.

If you go to church in Rio you will find prayer candles at the church entrance; white candles to the right and black candles to the left. In this country, undiminished by its various faiths, Catholicism mixes unselfconsciously with Voodoo-ism and nobody bats an eye.

And so it was one fine September morning that, after months of preparation, of parenting classes and proper diet, of the solemn purchase of cot, cradle and disposable nappies, we made our way up Corcovado to the private maternity clinic we had chosen, to meet the doctors and nurses who would deliver Tosh and set us on our way back down the hill to begin life with our new child and heir.

It didn't work out like that.

To begin with, Tosh just simply refused to budge. They tried everything but even the epidural didn't seem to work. The hours went by, we held hands and talked. People in white coats came and went. Things were attached and then later removed to be replaced by other things that looked much the same but weren't. The day slowly dissolved into the night. The ring-tails screeched at sundown and were heard no more until the dawn crept in across our private room and I studied the slow movement of the sun across the pale yellow ceiling. Then suddenly, in a flurry of trolleys, lights and white gowns and masks, it was all over. The wee man had arrived.

They didn't say anything at first. Gillian got to cradle him, so did I. He was the most beautiful baby I had ever seen. Then they said they thought there might be a problem, he was a bit flaccid and they wanted to do some tests. And then they took him away.

I phoned my mother with the news. There was a long pause. 'Son' she said 'you love him don't you'. It wasn't a question. 'Of course I do mum. How can you not love your own son? He's my wee man'.

Somewhere down in the streets of Rio someone was lighting a candle. It was me; in thanks.



Hats off to the Training Team

What has the Training Team been doing?

The Training Team has been offering free 'Mythbuster' general awareness training sessions to places such as museums, leisure centres, libraries, theatres, housing offices, job centres, shops and colleges. The intention has been to give information to staff who work in these environments and may have fairly regular contact with members of the public who have Down's syndrome.

In addition, some of the Trainers and volunteers have also been involved in more in-depth information events including hospital study days, school in-service training and training for support staff working in learning disability care services. Over the past 2 years the Training Team have designed and delivered training to at least 60 different organisations. It is an achievement to be very proud about.

Feedback from all of the training sessions has been excellent. Here are a few of the comments:

"It was very interesting and refreshing to have part of the training done by someone with Down's syndrome". Brothers of Charity.

"Good to hear from someone with firsthand experience". Stow College.

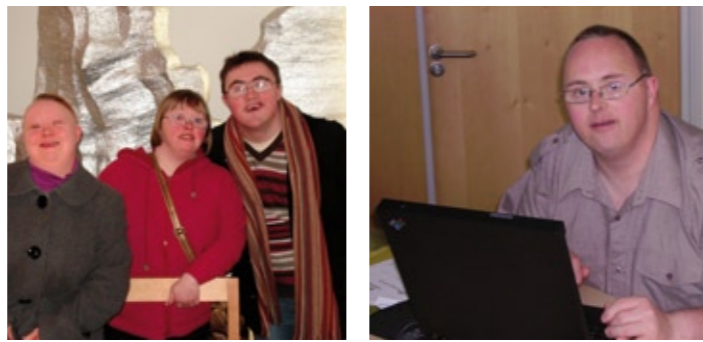
"The training reinforced that we should treat people equally". South Ayrshire Council.

"The training made me more aware that people with Down's syndrome are just like me". Grangemouth Sports Centre.

"It was good to have the input of someone with Down's syndrome and hear about their life". Pennypitt Special Needs Youth Club.

Training Team Workshops and Newsletter

Throughout the project, the Training Team have learned about developing training and what makes a good trainer at workshops organised on a regular basis in Glasgow and Edinburgh. The workshops are also a good opportunity for members of the Training Team to meet each other, share their ideas and talk about the training they have been involved in.



by **Brenda Hepburn** - Training Officer
And **Joanne Toner** - Trainer

The volunteers help to put together the Training Team Newsletter which goes out three times a year. Trainers and volunteers write articles for the newsletter not only about any training they have been delivering but also about issues and events that are important to them such as having a job, getting a house, holidays and their social lives. Joanne Toner agreed to answer some questions about being a trainer. **Tell us about the training work you have been involved in.**

"I have gone to the trainer workshops in Glasgow. I have put together presentations and talked at a Hospital Study Day, at Ibrox Stadium and I've done training for a local organisation called Threshold. I have also been involved in the 5 Nations Conference"

What does being a trainer mean to you?

"It is very important to me because I have talked all about my past and my life. For years I wanted to tell people my story and now I have a chance to do that.

I have learned a few things and made new friends. Training makes me feel very uplifted. I am glad people get the right information about Down's syndrome. Feedback was spot on and I was overjoyed about it".

Why is it important to do Mythbuster training?

"Down's syndrome is a fact of life. We cannot change it but we can change people's views. The Mythbuster tells the truth about Down's syndrome. Everyone has a right to live their lives the way they want whether they have Down's syndrome or not".



Sadly, the Training Project will end in mid July when the three year funding from the Big Lottery finishes. The funding enabled Down's Syndrome Scotland to employ a Training Officer and 14 Sessional

Trainers with Down's syndrome. In addition, 3 volunteers have worked with me behind the scenes to help make the project a huge success.

The Training Team will continue its good work and deliver the Mythbuster training up to June 2009.

News round up

West of Scotland Parent and Toddler Group

The group continue to meet on a monthly basis at the Albertslund Hall, Newton Mearns from 3 until 5 pm. Dates for 2009 are: March 15th April 26th May 17th June 14th September 13th October 25th November 22nd and December 13th.

Tayside Branch



Children from the Tayside branch enjoyed an outing to Sing n Swing and the Magic Hat. The children cast spells with the fairy, danced with the groovy dragon and met Mousie.... and all before lunchtime!

Congratulations to Christopher Newman

May Neeson was a founder member of the West Scotland Deaf Children's Society - a charity founded nearly 61 years ago. May dedicated an award - a cup which would be nominated annually to any deaf child who tried their very best in whatever way they could - it may be academically, on the sports field or indeed any way which showed they had endeavoured to do their best.



First place the award was given to Christopher Newman a young man who not only is deaf but has endured a series of operations and very difficult challenges over the past few years. Despite this, he always has a smile on his face and has grown up to be a son any parents would be proud of. A great credit, not only to himself; but to his Mum, Dad and big brother.

£ Fundraising



In Jan 2008 Joe Hughes decided to lose some weight before his 60th birthday in October. To keep at it he decided to raise money and along with lot help from staff and business friends Joe managed to get a lot of sponsorship. Joe set a target of losing 50lbs and achieved 46lbs. Joe might well have lost a lot of weight but he gained a massive thousand pounds for Down's Syndrome Scotland! Thank you.



Sarah Roberts and friends from Napier raised £120 through a wine tasting event – sounds great! Sarah's gorgeous nephew Calvin raised £140 back in December from generous family and friends. Thank you.



Sarah and Kathryn received a cheque for £430 from the boys at McNicholas. They raised this by winning a national work football tournament and were inspired to give it to Down's Syndrome Scotland by Charlie McGee's lovely niece Allison. Thank you.



New Resources from Down's Syndrome Scotland

Regular readers will remember Rhona Matthews' article on Teach

Reading to Teach Talking back in issue 90. Down's Syndrome Scotland are now pleased to announce that we have produced a manual and accompanying DVD which gives practical information on how the approach can help children improve their reading and language. **The manual and DVD cost £7.50 inc P&P and can be ordered From Kathryn at national office.**

Telephone 0131 313 4225 or email kathryn@dsscotland.org.uk

“the development of independence became one of the key targets”

Making Inclusion in School a Success

Laura is a young girl with Down's syndrome who attends a primary three class in a mainstream school in East Dunbartonshire, Scotland. Laura's parents and the Head teacher of Millersneuk Primary School share their experience of including Laura.

Millersneuk Primary School had no previous experience of including a child with Down's syndrome. When Karen Taggart requested that her daughter Laura attend the school they had initial concerns about how they were going to support her. The staff were aware that Laura had every right to attend her local school and realised that they would have to find out as much as possible about Down's syndrome before they could begin the planning and preparation process. Contact was made with Down's Syndrome Scotland and Karen Garrot worked with the school to provide them with information and support.

Karen (Laura's mum) felt that making the decision about what school would be best for Laura was very difficult and stressful. Laura's time in her pre-school year was split between a special needs and mainstream nursery. Laura has a twin brother, Ian, and the Taggarts felt very strongly that she should be given the opportunity to be in the same school as him. When the time came to decide on schools it was felt that Laura would benefit from an additional year in nursery during which she also received support from the preschool home visiting teacher.

Prior to starting school there were numerous transition meetings involving an army of professionals. This was sometimes overwhelming for the family as everyone had their own view, some supporting Laura's parents, others clearly not. However, Laura's parents had made their decision and ensuring that transition from nursery to primary school went as smoothly as possible became the priority.

Janice Callaghan, Head teacher of Millersneuk Primary School, was asked about the planning and preparation required when supporting a young person with Down's

syndrome in mainstream primary school. She said that she needed to know more information about Down's syndrome as well as from Laura's nursery. Therefore in addition to contacting Down's Syndrome Scotland they began to visit the nursery to gather information that would help them to set realistic targets.

It was important that Laura became familiar with the school and several visits were arranged to show her the various rooms that would become an integral part of her primary school life. Laura also went along to collect her brother at the end of the school day, becoming quite familiar with the playground.

In addition, a Learning Support Assistant was identified along with a teacher who would help Laura to settle in as quickly as possible. The school identified the correct resources and safety procedures which were then put in place before Laura started school. The school had also prepared excellent books for Laura to take home with pictures and words connected with the school.

Laura couldn't wait to start school. On her first day at Millersneuk Primary School her brother was very proud of her, and Laura happily waved goodbye as she went into the school. Her parents were in tears, this was a day they had looked forward to for a very long time. Laura was welcomed to the school like any other child and it had been a very positive experience for the whole family.

The school found that the main resources Laura would require were differentiated materials that would allow her to access the curriculum more effectively. Whilst this was initially time consuming, it proved an effective measure in supporting Laura's independence. It took time for her to settle but the school were pleasantly surprised in how quickly she actually coped with changes, particularly during transition periods.

It was important right from the beginning that the development of independence became one of the key targets. Staff at the school had to be creative in their learning approaches to Laura as well as ensuring that appropriate guidelines on risk assessment were looked at on a regular basis.



Head teacher Janice found that it is crucial to pre-empt potential challenges. “Every year it has been necessary to think about who would be the best teacher for Laura, it's important that you have the right person with the right attitude, someone who is willing to push the boundaries and will have high expectations. Transfer of information is vital and the parents should be involved throughout the decision making process. Target setting is never easy and needs to be talked over with the parents, being honest about abilities and potential achievements.”

When asked about the benefits of including Laura at Millersneuk Primary School, Janice was quick to emphasise that the staff have increased confidence, becoming good problem solvers. “They are creative and feel a sense of accomplishment with small steps being a cause for celebration. As a school it has been an absolute delight to have Laura as a pupil. Laura's peers have an appreciation that all children are different and that Laura is funny and a good friend. A whole school and classroom ethos has been paramount in making sure that Laura's inclusion is a success, realising that she is not a problem but rather an asset.”

For Laura, mixing with children who don't have disabilities has been very valuable; being able to copy and learn from other children and her speech has come on leaps and bounds. There is also a rich network of support from her peers to members of staff throughout the school.

Janice's advice to other schools would be to find out as much about Down's syndrome as possible, inviting Down's Syndrome Scotland to come out and visit the school to provide training. She said, “The school must have high expectations about what the child could potentially achieve with the correct support. A flexible and creative approach from staff is also vital. Strong relationships with the parents should be established starting with a position of trust and working in partnership with them throughout the child's school years.”

Finally, Janice remembers that when Laura first arrived she wondered if she would ever be able to read. Laura has indeed progressed to early reading, delighting everyone who is involved with her. Laura settled into primary one very quickly because the teacher and school were very well prepared for her. Laura's parents have regular meetings with staff, discussing Laura's Individual Education Programme. A home school diary helps Laura to communicate her news to the class. A visual timetable is used along with photos so that Laura can understand what is happening throughout the day. These photographs are also used at home so that Laura can tell her parents what she has done that day.

Laura is now in primary 3. She has two Learning Support Assistants who jobshare. They know when to intervene and when to step back and they encourage her independence enormously. Laura spends time with her whole class, small groups and one to one depending on her task.

She is making good progress with her tasks which are designed to challenge her and she is regularly rewarded with certificates and stickers to encourage and motivate her to do more. Laura loves books, stories, music, art, PE, computing and science. She enjoys being part of the school and getting involved in the many activities on offer to the children.

Laura has been taught to behave and play appropriately with her peers, she is valued and popular, making many friends and being fully included in school life. Laura's parents know that they have made the right decision for Laura, who is extremely happy and settled. As parents, the Taggarts know that the school have given a lot to Laura but also that she has given a lot back to the school. Inclusion has obviously benefited both Laura and the other children who are now more aware that we are all different and that *that* is a good thing.

Double Delights of Going to the Pictures

by Pandora Summerfield - Director



Shifting Perspectives is a photography exhibition that explores the photographic representation of people with Down's syndrome; challenging attitudes and prejudices and examining alternative representations of both adults and children. Now in its fourth year, the Down's Syndrome Association launches the exhibition annually at the OXO Gallery in London at the beginning of Down's Syndrome Awareness Week. The success of the exhibition is in its ability to challenge people's perceptions of Down's syndrome in a positive way, with new material being added each year. Shifting Perspectives is touring the UK through a three year sponsorship agreement with GlaxoSmithKline. We're delighted to be able to bring this remarkable exhibition to Scotland for what we hope will be the first (and hopefully not only) time.

The exhibition was established by a group of photographers who all have children with Down's syndrome. They wanted to combat the misleading and often frightening images of children found in old institutional text books. These images did not accurately reflect the positive and individual experience they had as parents. The initial phase of the exhibition was 365 images of three hundred and sixty five children with Down's syndrome, proving categorically that all children with Down's syndrome do not look the same! Yes, people with Down's syndrome do share common physical characteristics, but look more like their parents and siblings than other people with Down's syndrome. The message of 365 is equally represented throughout the whole Shifting Perspectives exhibition – that people with Down's syndrome are unique individuals who have their own ambitions, dreams, goals and personalities. The exhibition represents a snapshot into the life of a person who has Down's syndrome, either as the focus of the photo or as the photographer. The exhibition includes photography focusing on culture and diversity, weddings, relationships, employment and life in general.

“directly changing the perspective of the general public about Down's syndrome.”

Shifting Perspectives Exhibition.
The Filmhouse, Edinburgh
20th March – 5th April

Photography is often said to reflect society's attitudes and opinions, but it also serves as a powerful campaigning tool. It remains supremely influential even in the cynical digital era and perception of its links to the truth prevails. In an era where 'image is everything,' the power attributed to photography is immense. It not only determines the perception of the appearance of the individual, but also implies their personality and situation.



The Shifting Perspectives exhibition has been a resounding success in moving the image of people with Down's syndrome away from the Victorian negativity towards a more positive, realistic image of individuals who have Down's syndrome. Many of the people who have attended the exhibition

in London, did not have a link with Down's syndrome, but were merely passing and were lured in by the vibrant photography. It is through this type of connection that the exhibition has been able to have a huge impact – directly changing the perspective of the general public about Down's syndrome.

Despite much effort on our part to secure a Glasgow venue, we were unable to do so for the initial launch (many venues are booked up ten years in advance), therefore we have decided on the Filmhouse, Edinburgh. This is a great location as you can come in, have a look at the exhibition and enjoy a coffee in comfortable surroundings.

In addition, on World Down's Syndrome Day, the Filmhouse are screening the film Heavy Load at 6pm.



Heavy Load is about a punk band made up of five fantastic guys, some with learning disabilities and some without. Michael the drummer - a really interesting and thoughtful character - has Down's syndrome and he tells his story of how he ended up in the band. The film charts their journey from playing "disability venues" to ultimately playing the Wychwood Festival alongside some world famous bands. The film also addresses the social problems faced by adults with learning disabilities; due to their support needs they often have to be home by 9pm, when the party is only getting started. Heavy Load have started a campaign called 'Stay Up Late' which seeks to make a change in the system. This is a really enjoyable and inspiring film which shows that there are no limits to what you can do when you put your mind to it. Unfortunately the film is rated 12 and is not suitable for young children, but we would however recommend it to all young adults and above as we've certainly enjoyed it here in the office. A short version of the film was shown on the BBC in early February, but this showing is the full feature length version. The Filmhouse have given us the opportunity to host a discussion after the screening, so come along and add your voice and experience to the debate.

Spring gallery



- 1 Harry Potter – Jonathan Alps winning first prize in the Halloween fancy dress.
- 2 Penny and Rose moving house and Ring a Ring a Roses with friend Anna.
- 3 James and Stuart campaigning
- 4 Fraser relaxing at home
- 5 Arran the budding artist



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