

journal

Letter from the Chief Executive

A Happy New Year to all of our members.



Carol Boys

This Journal is packed full of interesting information as always.

You will notice that the DSA now has a small regional office in Exeter and a couple of new members of staff who are based there, Kate Jones, Communications Manager and Charlotte Knowles, Information Officer. There is also another new addition to the WorkFit team, Alexis Brown, based in the North and another appointment for WorkFit, yet to be confirmed for the Exeter office. We have been really fortunate to receive specific funding for WorkFit which will hopefully enable us to meet the increased demand for this brilliant service. There are features on all the new members of staff in the Journal.

The popularity of DSAActive continues to grow and we recently held our first Tennis Festival in Roehampton with 56 people with Down's syndrome taking part. The festival was the result of a collaboration between DSAActive and the Tennis Foundation. There is much more to read about the progress of DSAActive in the Journal.

The update on the changes to benefits through the introduction of PIP is very important and we are hoping that this

particular benefit will continue to be rolled out over the coming months in further geographical areas regardless of what happens on the political scene.

Through our work during the DWP consultation process, we were able to have some influence on the assessment criteria and generally people with Down's syndrome should be better off under PIP. This is particularly significant for people in supported living with a Personal Budget.

There is so much to read about our activities in all areas of the work that we do. It's just worth remembering that we do all this with only 37 members of staff, some of whom are part time.

Finally, I was really shocked to hear the sad news recently about the untimely death of a former Trustee of the DSA, Ann Hutchinson. I knew Ann very well and I first met her when she was a very active member of the then South West Thames branch, before she subsequently moved to Somerset. Ann worked tirelessly for her local group in addition to her role as a Trustee of the national organisation and she was a huge support to me and other Trustees through some very difficult times for the DSA.

The Hutchinson family has raised thousands of pounds for the DSA through various types of sporting challenges over the years and only a few days before Ann's tragic accident, they were planning yet another bike ride.

Ann was a lovely person with a generous spirit and she will be missed by all of us.

A handwritten signature in black ink that reads "Carol Boys".

Information for Contributors

The Down's Syndrome Association publishes the journal every September and February.

We are interested in publishing general articles, news, letters, academic papers, book reviews, arts/exhibition reviews and conference reports, all of which should be specifically related to Down's syndrome.

We include human interest stories on any aspect of life with Down's syndrome. Previous articles by parents have covered all stages of life from birth to adulthood. If you have an interesting story we would like to hear from you.

How to submit

Articles must be between 700-1400 words; be submitted in Word format; if possible include a photograph in .jpg format; include a short biographical statement about the author of no more than 25 to 30 words.

Articles submitted for consideration should be sent to:
Ian Jones-Healey, DSA Journal Editor
ian.jones-healey@downs-syndrome.org.uk

Deadlines

September Edition: 30 May /
February Edition: 30 October

General Notes

We cannot always publish articles as space is limited; articles may be published at a later date if the next issue is full; we reserve the right to edit articles; the Editor may alter articles wherever necessary to ensure they conform to the stylistic and bibliographical conventions of the journal; authors are responsible for the opinions expressed; if using references please use the Harvard system; photocopying single copies of articles contained in this journal for the purpose of private use is permissible; for multiple copies and reproduction, permission must be sought from the DSA/author(s); copyright is retained by the author(s); if authors use the same material in subsequent publications, acknowledgement should be given to this journal.

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Down's Syndrome Association Journal

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Disclaimer

Journal is designed to provide a communication forum for members of the DSA through which to facilitate the exchange of information on topics related to living with Down's syndrome. Unless indicated otherwise, the views expressed in Journal are those of the authors and do not necessarily reflect the official positions or policies of the Editor or Down's Syndrome Association.

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On the Cover: George Karol Armour who was born on 4 November 2014. See page 32.

New staff

Kate Jones | Communication Manager



Before joining the DSA in October 2014 as the new Communications Manager, Kate was Executive Producer at BBC Worldwide, where she managed production teams in both traditional and digital publishing. Having worked in publishing and advertising both in the UK and USA, Kate comes with more than fifteen years of communications experience.

Kate says:

"I am proud to be part of a circle of support for an adult with Down's syndrome and have

been involved with the DSA for many years both professionally and personally. The services and support provided by the DSA are invaluable and it is extraordinary to see how much is achieved by a relatively small group of people who work for the association. I am endlessly impressed by the dedication and enthusiasm of everyone who works for the DSA and am delighted to be part of such a great team. I'm looking forward to raising even more awareness of the charity and its fantastic work."

Alexis Brown | WorkFit Employment Development Officer



I was attracted to the post of Employment Development Officer because of the organisation's positive, information based approach to supporting people with Down's syndrome and their families from pregnancy, birth, through the childhood years and into adulthood.

I was particularly impressed with the WorkFit programme which treats people as individuals and offers them the opportunity to consider their career choices, rather than being slotted into work or volunteering that would not necessarily suit or benefit them, or the organisation.

Since taking up the role of EDO for the North East and North West of England, I have been concentrating on employer

engagement; making links with, for example, local authorities, business forums, community and voluntary sector, chambers of commerce and the private sector.

I have met with candidates in the Manchester area and am currently making contact with candidates who have registered with WorkFit. I am looking forward to meeting up with them when carrying out individual assessments and through local support groups.

I am keen to engage with employers and would like to see more in the North East and North West taking WorkFit to heart and embedding it into their organisations as a model for the recruitment and retention of employees with Down's syndrome.

Charlotte Knowles | Information Officer



I come to the DSA with what can only be described as an eclectic background. On a personal level, I have lifelong experience of issues facing people with physical and learning disabilities, having volunteered at my dad's workplace (residential care for people with disabilities), and through family friends. I grew up in a family where prejudice was challenged, being an active community member was encouraged and individuality was valued. This background remains hugely influential in relation to work and life in general.

I originally qualified as a linguist with the aim of working abroad: I spent a summer working

with children in Germany before completing an internship at CERN in Geneva, followed by a stint in Brittany.

I then spent a number of years working in industry, focused on export marketing and shipping, eventually joining a project team delivering change management in enterprise resource planning in the UK and overseas.

Combining my language skills with developing people changed my perspective on what I wanted from a job leading me to seek a new direction.

My next role was at the Commission for Patient and Public Involvement in Health where I led a team of staff recruiting volunteers to have a say in health service delivery in their local areas, with a particular focus on community empowerment for traditionally excluded service user groups. At the same time, I also used my language skills volunteering for the British Red Cross working with refugees and asylum seekers.

After being made redundant I trained in social work to increase my skills and knowledge in working with people.

Until recently, I have worked in children's services, where I have established a detailed knowledge of service delivery, policy and the diversity of family lives. This has included working with parents and children from a wide range of backgrounds in a variety of circumstances, quite often in times of crisis and stress.

My long-term aim as a social worker was always to use the training, skills and knowledge acquired in the not-for-profit sector and I am now really excited to be joining the information team who have an amazing depth of knowledge and skills, which is quite intimidating to a newcomer. I am hoping that my existing knowledge of policy, legislation and practice may be a useful addition to this. I realise that I have a lot to learn – especially from people who use the services of the DSA.

Teddington School Volunteers



Photograph from left: Winnie Miles, Emilie Craddock and Saskia Whittaker

The DSA has recently had the exciting opportunity to develop a relationship with the new sixth form at Teddington School.

We have been delighted to welcome three student volunteers from Teddington Sixth Form to the DSA team: Emilie Craddock, Winnie Miles and Saskia Whittaker.

The students have been volunteering and supporting the Down2Earth Magazine,

the DSA website along with the fundraising and finance teams. All of the students have been very enthusiastic, hard-working and full of ideas, and we are very pleased with how they've been assisting our work.

We wish them every success in the future.



DSActive News

By Scott Pollington Woods, DSActive Sports Manager, DSA

The past twelve months have been very successful for DSActive as it entered the second year of the three year 18+ sports programme. Fulham FC Foundation launched adult tennis sessions, while new adult football teams have started, five from existing DSActive partners and five with new partners. The programme held two major events; the DSActive National Festival and the Coach Ability Programme.

The DSActive National Festival

The DSActive National Festival took place for the fourth consecutive year on 29 June 2014. The event, which brings together DSActive football teams from across England and Wales, took centre-stage at St George's Park in Burton-upon-Trent. A record 16 DSActive teams took part in a fiercely contested and high-quality contest, with over 150 players battling it out to be crowned champions! The tournament provided an exciting spectacle for the several hundred coaches and family members watching from the sidelines.

The teams took part in a round-robin style tournament, followed by a semi-final stage and a final. One team would progress from each of the three groups, with the runner-up from the Red Group also progressing. Each match lasted 12 minutes and was played six-a-side. The groups were as follows:

- Red: Cardiff City DS Bluebirds, Lincoln City, Norwich City DS Canaries, Northampton Town, QPR Tiger Cubs
- Blue: Coventry City & Sheffield United, Derby County, Fulham Badgers, Newcastle United Foundation, Moorside Rangers Blue
- Yellow: Hull City DS Tigers, Ipswich (Inspire Suffolk) Mini-Tractors, Moorside Rangers Yellow, Watford FC, West Bromwich Albion

Matt Maguire, DSActive Sports Officer, shared his opinion of the event:

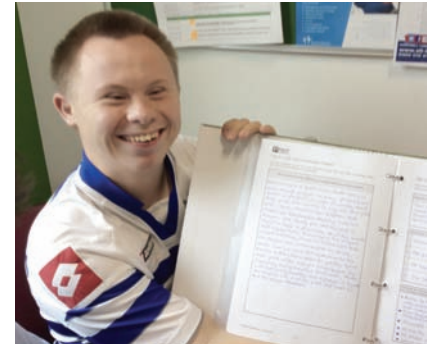
"We had an absolutely superb time, and from what we can tell everybody shared our enthusiasm. The National festival has run for four years consecutively and this was without doubt the best yet, the increase in quality obvious to all in attendance. Furthermore, the spirit and friendliness shown from all of the players on the day was superb and added only to an incredible day. Credit must go to all coaches, players and parents."

Coach Ability Programme

On 4 July 2014 six adults with Down's syndrome from across the UK proudly held certificates above their heads and congratulated one another on an amazing four weeks. These six people, all regular participants in football sessions with DSActive, three from Cardiff City DSActive Bluebirds, two from QPR Tiger Cubs and one from Fulham Badgers, had just completed their FA Level One Certificate in Coaching Football.

The course, which was the first coaching course adapted specifically for the needs of people with Down's syndrome was delivered by experienced tutors from the Birmingham FA and took place at the Portway Lifestyle Centre in Oldbury.

The players faced a demanding 30 hours of work spread over 6 sessions, where they learned the fundamentals of developing youth and adult players, how to organise sessions safely, high quality delivery of coaching sessions, and workshops in emergency aid and safeguarding vulnerable people.



Over the four weeks, participants faced a number of personal challenges including conquering anxiety of talking to large groups of people, managing intense classroom theory and learning to share and develop ideas collaboratively with their peers.

"The dedication and motivation from all the candidates was incredible" said Matthew Maguire DSActive Sports Officer,

"throughout the four weeks the players were supporting each other, giving feedback and urging each other to be the best coach they can, it was fantastic to see."





As part of the final assessment, each player had to plan, deliver and evaluate a 15 minute coaching session to his peers, all under the watching eye of the FA assessor, Nigel Latimer. The hard work and commitment of the players was evident though as all of the practical sessions were considered to be of a remarkably high standard by the assessor, who gleefully passed every single participant on the course. Nigel later commented

"I was overwhelmed by the level of commitment from all six of the candidates, along with a brilliant attention to detail. These are important qualities for a coach to have and I'm sure they will make excellent coaches in the future."

Following this huge achievement, it is hoped that the players will start roles as assistant coaches at their DSAActive clubs, and even lead sessions in the near future. Conor McBrearty,

head coach at the QPR Tiger Cubs, who put forward two players to take the course, declared

"I'm so proud of the lads for passing their FA Level 1 Course, they were a pleasure to work with and Alex F and Alex W will be more involved in coaching capacities at our weekly sessions next year, where they will act as role models for the younger players."

It was a very successful four weeks for all of our players who have performed so magnificently to pass the qualification and we hope to replicate this course in the near future. Rav Bhandal from the Birmingham FA agrees that this was a huge success saying

"The BCFA are extremely proud to have hosted the first ever 1st4Sport Level 1 Award in Coaching Football exclusively for candidates with Downs Syndrome. It was a great course and we are delighted to announce that all candidates passed. I personally would wholeheartedly like

to thank DSAActive for providing us with this opportunity and look forward to the next course already."

Both DSAActive and the Birmingham FA are interested in running the course at least once annually to give as many people within DSAActive the opportunity to gain both a qualification and indeed employment in sport. DSAActive tennis partner, the Tennis Foundation (TF) have also expressed an interest in replicating the course in tennis; an event that will likely take place in 2015.

Tennis

The DSAActive programme hosted its very first National Tennis Festival on 1 November in partnership with the TF. The event, which took place at the National Tennis Centre in Roehampton, was the very first of its kind and, after great interest in the event, is likely to become an annual fixture along with its footballing counterpart.

My Perspective Photography Competition 2015



2014 Winner: Stephen Thomas, Moraine Lake



Runner Up: Tim Beale, Chilling Out



Runner Up: Rosika Edmund, Flower Poem

Who is the competition for?

The competition is open to anyone with Down's syndrome. All we ask is that you take the picture yourself. We want to see pictures of anything that interests you. We are all very excited to see what amazing entries we will receive.

How do you enter?

The competition for 2015 is open now, so start taking pictures and maybe you could be next the 2015 My Perspectives winner.

You can enter 3 pictures (per person). Please submit an entry form with all images and a brief story about each image and why it is important to you.

All submissions must have an entry form.

You can apply in one of three ways:

Online: complete the online entry form and upload your images.

Email: download and complete an entry form and send with your images to:
myperspective@downs-syndrome.org.uk

Post: download and complete an entry form and post with your images to:

My Perspectives Photographic Competition, Down's Syndrome Association, Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex TW11 9PS

To access entry forms and upload images go to:

DSA website www.downs-syndrome.org.uk, click the section **For People with Down's Syndrome**, and then **My Perspective Photography Competition**.

All images need to be at our national office by Friday 24 April 2015.

Images received after this date will not be entered into the competition.

Unfortunately, images cannot be returned unless sufficient postage is included.

The shortlisted entries will be notified by Friday 15 May 2015.

The winning entries will be announced at an exclusive awards ceremony in London in June 2015.

Prizes will be awarded to the winner and 2 runners up with all shortlisted entries receiving special highly commended prizes.

All entries will be judged by a panel of professionals.

Don't delay, start snapping away today.

News from Wales

Julian Hallett, Down's Syndrome Association Wales Manager

The focus on training delivery across Wales has continued over the autumn and into 2015.

Julian Hallett, Wales Manager, has continued to expand new courses for health, education and social-care professionals, with courses focusing on adults with Down's syndrome and those who are ageing, in particular demand. Courses have been facilitated for a number of local authorities including Powys, Monmouthshire and Conwy. We have also been working with a leading Housing Association in Wales to train their workforce in meeting the needs of older people with a learning disability.

Work in schools continues with a particular focus, over recent months, on work in secondary schools, as a cohort of children with Down's syndrome in mainstream primary schools prepare for this important and exciting transition. We were fortunate to receive funding to deliver a number of workshops on 'Promoting Positive Behaviour' for professionals and family-carers to attend. The first one, held in Mid-Wales, was extremely well received. More are planned for the coming months.

Our WorkFit Wales project goes from strength-to-strength. Our official public launch in the autumn saw widespread media coverage of this new Wales service and Simon James, the Development Officer, is now working with upwards of 20 young people across Wales aged 14-25, who are undergoing candidate assessments. Simon is simultaneously



Julian at a WorkFit promotion event

beginning work with employers across the region and we hope to report back our first placements in the coming months.

A significant amount of work has also been invested in setting-up an external evaluation of the project with a team of university-based researchers. In November Julian and Simon led a workshop on employment opportunities for young people at the Learning Disability Wales annual conference.

In North Wales, our Development Officer, Jane McIlveen, hosted a very successful new families residential conference, which was attended by more than a dozen families from across the region. We will now be following up on this event with individual assessments for the children

who attended, by working with our colleague, Gillian Bird. Jane is now embarking on a GWIRVOI funded volunteering project which will match young people with Down's syndrome with non-disabled peers in a number of North Wales schools and colleges.

I am delighted to report that one of our long-standing parent-members, Mike Pickard, who until recently led our South East Wales Support Group, was acknowledged in the latest *Understanding Disability Awards* under the *Lifetime Achievement* category. A well deserved accolade for a stalwart supporter of inclusion for people with Down's syndrome both locally and nationally and internationally. Well done Mike!



A training session in full-flow

Down2Earth

Amy Deakin, Information Officer, Down's Syndrome Association



The Down2Earth group. Photograph by Nadia Bettega

Who are Down2Earth?

Down2Earth is a focus group of adults with Down's syndrome. They meet every month at the DSA's Head Office in Teddington, discussing different topics that inform our work and give people with Down's syndrome a say in what we do. The group also has a lot of fun, too!



Ketakee and Krystina

Down2Earth update

Down2Earth helps the DSA include the voice of people with Down's syndrome in what we do. For example, their opinions and decisions helped us develop the Health Book for adults with Down's syndrome. Here is an update of what the group have been up to recently:

Down2Earth have been involved as a focus group with POSEIDON, a three year EU-funded research project that aims to create information technology to help people with Down's syndrome achieve a greater level of independence in their lives. You can find out more about POSEIDON on their website: www.poseidon-project.org.

Down2Earth also played a key part in the new look Down2Earth Magazine, which was sent out to DSA members last September. The group initially told us what kinds of magazines they enjoy, what topics they like to read about and which designs they prefer. They then created their own magazines. Using

these ideas, we came back to the group with some draft versions, and the group selected their favourites. Their thoughts and choices helped us create the final version – and we hope you like it as much as they did!

Down2Earth are now helping us create a booklet on self-esteem for teenagers and adults with Down's syndrome. The group discussed how to know when you're feeling low or sad, suggestions for staying positive and ways to boost your self-esteem.

We also talked about relaxing and peaceful places. The group had lots of great ideas about how to de-stress, including: talking through problems, being with positive people, watching TV (Mr Bean and Grange Hill were particular favourites), spending time with friends who are feeling down, counselling if you need it and exercising.

The self-esteem booklet will be available in the near future – so watch this space.

Being Interactive

Down2Earth has also been getting more interactive, and we are now using iPads with the group. Interactive technology helps Down2Earth get more engaged and 'hands on' with testing things out, as well as being a lot of fun! At the moment, the group have been testing our new web pages for people with Down's syndrome, looking at accessibility, content, how they use the internet and what else they would like to see. Take a look at the new website: www.downs-syndrome.org.uk/for-people-with-downs-syndrome.

Sharing what we do: Down2Earth's video blog

Down2Earth has recently started a video blog. Blog features include discussions on how to look after your self-esteem and feel positive, looking at websites and technology, and much more.

Visit the blog at:
down2earthgroup.london.wordpress.com

New web section for people with Down's syndrome

Along with the rest of our website, we've updated our pages for people with Down's syndrome. These include accessible information on subjects such as benefits, health and travel, fun activities, sport, finding a job and much more. We are now looking for feedback on the new web pages and will be surveying members with Down's syndrome to find out what they think. We will also be doing further work with the Down2Earth group.



Down2Earth Magazine

You're probably familiar with our magazine for people with Down's syndrome: Down2Earth Magazine. February 2015's edition is an exciting issue, with interviews, activities, artwork, articles, stories, photos and much more. We are now looking at new ways of keeping the momentum going and creating more opportunities for people with Down's syndrome to have their say, so watch this space!

Down2Earth Magazine is always looking for more people with Down's syndrome to write for the magazine. If you or someone you know would like to send in an article, photo, poem, story, letter, review, or something entirely different, please email the editor Kate Powell at Kate.Powell@downs-syndrome.org.uk.



The Down2Earth group



The Down2Earth group working with an iPad



Down2Earth editor Kate Powell

Finally, a big thank you to our Down2Earth volunteers

We have recently had two fantastic volunteers join the Down2Earth team. Nadia Yaseen supports Kate Powell with her blog every week, helping her with grammar, punctuation and putting her writing on the blog. Emilie Craddock, who attends Teddington School Sixth Form, is also helping us develop the 'people with Down's syndrome' section of our website. We would like to say a big thank to both volunteers for all their ideas, hard work and enthusiasm.

WorkFit Champions

Connecting Employers and Employees with Down's syndrome

Veronica Mulenga, Employment Development Manager, DSA



Sam is 25 years old and works for Omega Training Services Ltd in Birmingham.

He has been working there since September 2013 as a paid Office Assistant. Sam works two days a week (14 hours) and has fitted really well into the team. His tasks included shredding, photocopying and putting together training packs. He has also been involved in welcoming visitors to the offices and making their drinks.

Sam is a very outgoing friendly person. He always throws himself wholeheartedly into everything he does. He is patient, persistent and doesn't give up. Sam is very helpful and has often been told he would make a good mentor.

Local Support

We are looking to support young people and adults with Down's syndrome access meaningful work opportunities that can benefit the rest of their lives but we need your eyes and ears, your local knowledge and your on-going support to help us achieve this. We are guessing that for every young person with Down's syndrome there is a parent/relative/friend who works, who could potentially ask at their place of work? Do you know of inclusive employers, employers who are currently or who have the potential to support people with Down's syndrome?

Tell us who the employers are

Please contact the WorkFit team on 0333 1212 300 or email us on dsworffit@downs-syndrome.org.uk
For more information visit the WorkFit website www.dsworffit.org.uk



Katherine is 26 years old and works for Browns Hairdressing Group in Olney.

She has been working for Brown's Hairdressing Group since February 2013 as a paid Salon Assistant. Her tasks include meeting and greeting clients, cleaning the waiting area and washing, drying and folding towels and gowns. Katherine enjoys rhythmic gymnastics and works hard to compete at Special Olympics competitions using ball, hoop, ribbon and rope in her routines to music.



Krystyna is 34 years old and works for Travelodge in London.

She says: "My name is Krystyna. I am 34. In my spare time, I like to watch football, go to zumba and listen to music. I like Magic FM because I can relax. I also like to go out with Aurelia, my niece. I work in Travelodge. I get there on the bus. My job is to take people for breakfast and I also clean the tables. Sometimes I do the drinks menus as well. I wear a uniform and sometimes I have difficulty with my name badge. It has a pin in the back and I don't want it to make a hole. I like my job because I get paid and I want to work. I like to meet people. You always have to be kind and polite and respect people. I am always on time and I always get up on time. My gran makes sure I'm ok. My dad gets up early and gets my breakfast."

Prem is 20 years old and also works for Browns Hairdressing Group in Buckingham.

Prem started working for Browns Hairdressing Group in June 2012 one day a week for 3 hours whilst he still attended school in Aylesbury. Since January 2013 Prem has been working three days a week for 16 hours. Prem has multiple tasks that have increased since joining the team in 2012. The tasks centre on house-keeping jobs such as organizing the towels, sweeping the floor and cleaning the many mirrors. All of which he does with meticulous attention to detail. Prem loves getting paid as it allows him to go out on trips and pay for his own meals and clothes. He has become more confident and independent. Prem's mum has noticed the changes and benefits. She says:

"Premal has become much more independent. He has really changed and his demeanour shows that he is really happy at work, and he feels more a part of society with the responsibilities he has gained and what is expected of him".



Stefanja is 17 years old and has been working for JoJo Mama Bebe in Cheltenham as a Shop Floor Assistant since June 2014.

She works one day a week. This is Stefanja's first job and her tasks have increased since she started. This opportunity has allowed Stefanja to learn about her responsibilities as a paid employee, work on her initiative and also to be more independent at work. When asked what job she would like to do after school and why, she says

"I would like a job as a sales assistant. I would be good at this because I enjoy meeting people and I am a happy person. Having a job is important to me because it will make me a little more independent".



Stefanja likes to keep fit by swimming and has raised money for her local hospice by swimming 36 lengths in half an hour.

Thomas is 20 years old and works for JoJo Mama Bebe in Newport as a Warehouse Assistant.

Thomas started at JoJo in March 2014 working one day a week for 4 hours. After 5 months he has increased his hours to 13.5 having finished his college course. His tasks include: labelling with bar codes on product tags, picking up store orders, recording them and keeping the warehouse clean and tidy.

Thomas really enjoys sports especially football. He currently plays for Cardiff City Disability team. In 2013 a goal that he scored was voted "The Goal of the Season" for Cardiff City which he is extremely proud of. He also plays for Pontllanfraith Dragons.



Photographs by Mariana Melo Lima

Exploring the photographic representation of people with Down's syndrome

We have produced a celebratory book commemorating **Shifting Perspectives**.



The images in this book draw upon many different themes, from intimate family life, to asking if Down's syndrome occurs within every race or culture. People all over the world are now seeing our images and my hope is that the public will be able to see that people with Down's syndrome have dreams, aspirations, wants, needs, likes and dislikes, just like anyone else and through these images they will see an individual, rather than just a person with Down's syndrome.

Richard Bailey
Curator of Shifting Perspectives

Shifting Perspectives is a body of work of great integrity; it confronts our preconceptions and assumptions, but it is also tender. This book is full of stories and photographs that both challenge our expectations and re-position our perspectives, but even beyond issues related to Down's syndrome, it tells human stories that are of relevance to everyone who has to negotiate the unpredictable path through contemporary society.

Susan Andrews
Senior Lecturer in Photography London Metropolitan University

Order your copy of Shifting Perspectives for £15 + £5 postage and packaging

Online www.downs-syndrome.org.uk

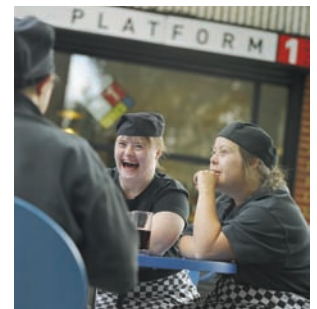
Telephone orders Call 0333 1212 300

Orders by post Enclose a cheque made payable to the Down's Syndrome Association and send with your address to:

Publications, Down's Syndrome Association, Langdon Down Centre,
2A Langdon Park, Teddington, Middlesex, TW11 9PS



Photograph by Richard Bailey
2005 | 365: the individuality of people with Down's syndrome



Photograph by Richard Bailey
2006 | Birth to Adulthood



Photograph by Fiona Yaron-Field
2007 | Showing that people with Down's syndrome have hopes and dreams like anyone else



Photograph by Richard Bailey
2008 | Culture, beliefs, and desires: challenging the myths about Down's syndrome



Photograph by Fiona Yaron-Field
2009 | Life with friends and family: an intimate window on everyday interactions



Photograph by Fiona Yaron-Field
2010 | Adulthood and human rights



Photograph by Fiona Yaron-Field
2011 | Back to basics – pregnancy and birth



Photograph by Richard Bailey
2012 | WorkFit

Remember Your Will

Alison Morgan, Fundraising Manager, DSA

Writing your will is generally an activity that most of us will put off doing. There is always something more important or enjoyable to do. However, not writing one can cause difficulties for those closest to you and means the law decides what happens to your estate and how it is distributed, taking away your choice as to where and who your money goes to. Obviously it is always important to ensure that all your loved ones are remembered in your will but, we would ask if you could then consider leaving a legacy to the DSA so that we can plan more effectively for our future.

Leaving a legacy is an important decision that you don't want to take lightly so we hope the following information will help you with the process.

We have spoken to our legacy expert, Vernon Feakins and he has answered some of the most common questions about writing a will and leaving a legacy.

Can I write a will myself?

It is possible to write a will yourself but it is not advisable as the legal requirements may not be followed properly, thus invalidating it. It's much easier and safer to get this done professionally. We always recommend using a solicitor who will explain the whole process and can ease any of your concerns or queries.

Doesn't it cost a lot of money to get this done professionally?

It really depends on the type of will. If it's a very simple will then it might

cost as little as £50 but it could cost considerably more depending on the size of the estate and the amount of recipients named in the will because it will be based on the solicitor's time involved in writing the will and their expertise.

The cost of writing a will may seem expensive at first, but if you wish to ensure your wishes are carried out correctly, the cost is a small sum in comparison to getting it wrong. We recommend asking a few solicitors for a quote so that you can obtain the best price for the service. All solicitors have to carry professional insurance cover so if they happen to get it wrong it won't affect your estate when the time comes.

Are there inheritance tax (IHT) advantages if I leave money to charities?

Giving assets to charity through your will is one of the easiest ways to reduce your IHT liability, as all gifts to UK registered charities on death are completely exempt from IHT. A gift of £10,000 to a charity can reduce your IHT bill by £4,000. You can be flexible – you can make cash gifts, or specific gifts of, say, a property or shares. You can give a charity a share in your estate, or the whole estate. All these gifts are wholly exempt from IHT.

Is there a minimum amount that you can leave as a legacy?

Absolutely not. Any amount can make a big difference. Some people leave

relatively small legacies whereas others leave their whole estates to charity.

Here are some examples of the types of legacies that can be left:

- A share of your estate. You can leave a share, or the remainder, of your estate to us after you have provided for your family and friends. This is called a 'residuary gift'.
- Cash gift. You can leave an exact sum of money to us which is known as a 'pecuniary gift'.
- A specific gift. Anything from your estate could be left to a charity – this could be as much as leaving your house to be used for people with DS or a small piece of jewellery.
- A gift in trust. You can leave a gift for someone to use over a period of time – usually their own lifetime. When the time has ended, the gift can be passed on to other recipients, such as a charity

I have already made my will but would like to change it or add a legacy to the Down's Syndrome Association – is this possible?

Yes. If you have made a will, but need to make changes to it or you would like to add a gift to The Down's Syndrome Association (DSA), this can be done by means of a codicil. This is an addition to your will and can change or amend anything in the original document. Again your local solicitor will be able to help you put this together.

If you are interested in receiving any further information or you would like any advice about leaving a legacy please contact our Fundraising Manager, Alison Morgan on 0333 1212 300 or at Alison.Morgan@downs-syndrome.org.uk

Benefits News

Christina Katic, Benefits Adviser, DSA

Personal Independence Payment (PIP)

As many of you know, the replacement for Disability Living Allowance, PIP, is being introduced gradually in different areas of the country. From 17 November 2014, existing DLA claimants in four additional areas will be "invited" to claim PIP if:

- the DWP gets information about a change in their personal care or mobility needs, or
- their DLA award is about to expire, or
- the claimant turns 16, or
- the claimant chooses to make a PIP claim.

The additional areas are postcodes beginning with: CH (Chester), HD (Huddersfield), L (Liverpool) and M (Manchester).

Remember, as long as you respond to the "invitation" to claim PIP, saying you want to make a claim, your DLA will remain in payment until the PIP claim is fully assessed. PIP is only for people of working age. Children and people over 64 are not affected.

For the latest information on Benefits see the pages on our website at: www.downs-syndrome.org.uk > For Families and Carers > Benefits and financial help

DSA Fundraising

BFG Update

You may have noticed that there's something missing with this edition of your DSA Journal – there's no BFG. After much discussion we have decided to discontinue the BFG, saving the DSA vital cash and making us that little bit friendlier to the environment. From now on we'll be using our website, social media feeds and a new fundraising e-newsletter to let you know what the Fundraising Team is up to.

We still want to hear all about what you're up to too! Please email your photos and fundraising stories to Alexa Dizon at: alexa.dizon@downs-syndrome.org.uk

Please email info@downs-syndrome.org.uk if you don't already receive our e-newsletter, and don't forget to like us on facebook www.facebook.com/DownsSyndromeAssociation and follow us on twitter [@DSAInfo](https://twitter.com/DSAInfo).

Celebrating 10 Years of Fundraising

In November 2005 Danny Mardell, a very active parent member of the DSA, died suddenly. Danny was also a very dedicated fundraiser and since his death, the Mardell family have continued his legacy raising an incredible £60,000 for the DSA.

Of this £60,000, £15,000 was raised in October at the most recent Danny's Challenge boxing event, where Danny Jr took on Mark Potter knocking him clean out!



Danny knocking out Mark Potter. Photograph courtesy of Daniel Baker Photography

This June will see the tenth and final Danny Mardell Knockout Challenge take place at The Boleyn Ground, home to West Ham United FC. It will also be the final time you will get the opportunity to play on this historic pitch before the Hammers make the move to the Olympic Stadium in 2016.

This year's event will take place on Saturday 6 June and further information can be found on our website.

We would like to take this opportunity to thank Carol, Danny Jr and the Mardell family for their continued support.

Join TEAM21

Since January we've been inducting all our fabulous fundraisers into Team21. From now on you'll notice Team21's logo on our fundraising materials and merchandise, and we need you to help us get as many people involved as possible. Whatever you're doing, whether its wearing your odd socks or running a half marathon, make sure you tweet about it – let's get [#Team21](https://twitter.com/Team21) trending this Awareness Week!

Events Calendar 2015

We have lots of exciting events for you to take part in this year and just a few of the big ones are listed below. There are plenty more on our website under Get Involved and we are always on hand to offer you advice and provide you with any fundraising materials or merchandise you may need.

March

- 16 - 22 Down's Syndrome Awareness Week
- 21 World Down Syndrome Day
- 22 BIG STEP FORWARD
- 28 Vision Wild Run #Team21

April

- 26 Virgin Money London Marathon #Team21

May

- 2 - 3 Isle of Wight Challenge
- 16 Spartan Sprint, Allianz Park
- 23 - 24 London to Brighton 24 hour Challenge
- 25 Bupa London 10,000

June

- 6 Danny Mardell Knockout Challenge
- 6 - 7 Trekfest The Beacons
- 20 & 21 Spartan Sprint and Super, South Wales
- 27 - 28 Grand Union Challenge
- 28 Capital to Coast Bike Ride

July

- 4 & 5 Spartan Sprint and Super, Manchester
- 18 & 19 Spartan Sprint and Super, Scotland
- 22 - 26 London to Paris #Team21

August

- 2 - 3 Prudential Ride London #Team21
- 8 - 9 London Triathlon

September

- 5 Spartan Sprint, Cambridge
- 5 - 6 Trekfest The Peaks
- 12 - 13 Thames Path Challenge
- 13 Bupa Great North Run
- 19 & 20 Spartan Sprint and Super, East Sussex
- 27 Spartan Beast, East Sussex

If none of the above take your fancy then why not organise an event of your own? If you have any questions or would like some advice, please get in touch via email: info@downs-syndrome.org.uk with Fundraising as the subject or give us a call on 0333 1212 300.

ACCESS Services

Hannah Patterson, Access Project Practitioner

Assessments, School Support, Training

The Access Project aims to equip individuals with Down's syndrome, their parents and carers, and other professionals with up-to-date information, support and advice around all aspects of development and education.

We hope to help promote development and enhance the quality of life for children and adults with Down's syndrome and work with support groups, families and institutes of education at a national level.

Access: assessments

The Access Project team offer one-to-one assessments for children and adults with Down's syndrome. Hosted at our head office in Teddington, these 2 hour sessions are an informal way of getting to know you and your child. We will look at existing skills, how to build on these and developing new skills. Our assessments include advice and recommendations that focus on academic, social and self-help skills. Individualised written reports can also be provided.

Access: school support

The Access Project team offer in-school assessments for children or young people with Down's syndrome. Following an observation/informal assessment, findings and recommendations are discussed with all relevant parties which can include our participation in planning meetings with both staff and parents.

The advice we are able to offer includes:

- Teaching methods that use children's learning strengths to support academic success
- Ways to support social development and behaviour, including friendships
- Inclusive strategies to help children and young people access the curriculum and learn with others

New for 2015!

Access: Visual resources

The Access Project team are in the process of creating downloadable resources to support language, literacy, numeracy and behaviour. These will



be freely available to members via our website in 2015.

We are currently collating examples of tools that have previously been used to help individuals access the curriculum. Each example, activity and resource will have an explanation to include background on why, when and how it was used to support learning and development.

These resources will build on the guidance provided in our Primary and Secondary Education Support packs as well as our Celebrating Success series.

Access: training

The Access Project team is able to offer a mixture of scheduled and bespoke training around all aspects of development and education. All of our training is built on evidence-based practice.

Scheduled training: We are currently running 5 scheduled training events:

- **Supporting Early Development:** birth - 5 years. Delegates will be given information on how to support infant

development through interaction and play; encouraging communication and language development; and how having Down's syndrome might affect development.

- **Support and Practice in early years & primary or secondary education.** Delegates will learn about the specific learning and language profiles of children with Down's syndrome, and advice and strategies for supporting learning and development in the early years and primary education or secondary settings.
- **Supporting Social Development and Behaviour.** Delegates will be given information on how to support social development and positive behaviour from ages 2-11 years or 11-18 years with practical advice and strategies.

The costs of these events are £40 for parents and £115 for practitioners.

Further details can be found on the training pages of our website; including dates, booking forms and programmes for each of the events.

To find out more about how the Access Team can help you, please email us at training@downs-syndrome.org.uk

POSEIDON

Since the last Journal, there have been exciting developments in the European POSEIDON project.

In August last year, we met with the project team in Mainz, Germany, to test some technology prototypes. The project team consists of members from DSA UK, the national Down's syndrome associations of Norway and Germany, technology and research companies from Norway, Sweden and Germany and a group from Middlesex University London called GOODIES (The Research Group on Development of Intelligent Environments). GOODIES is led by Professor Juan Carlos Augusto who is proud to be working in conjunction with the DSA. He says:

"The POSEIDON project has completed the first of its three years and at this stage of the project the teams are developing technological support for the home to prepare for a trip, apps to train for work or school activities as well as travel support to go from home to their destination. Once this has been consolidated the project will increase support in different scenarios outside home, for example, socialization, work and education. We firmly believe people with Down's syndrome have a lot to give to society if they are provided with the right support and they are given a chance. We know POSEIDON will not solve all the problems, however we have hopes it will increase awareness of the capabilities of this group of citizens and their willingness to realize themselves as individuals. This project will also help us all to better understand the ways we can support them with technology in the future."



A Tai Chi display from one of our German guests.

In January 2014 the project team met with four people with Down's syndrome who were invited to talk about themselves and the technology they already used in their everyday lives.

We met Serena (39), a Global Olympic Messenger from Italy; Gregor (22) from Slovenia who loves computer games and his exercise bike; Vicki (15) who will soon be training as an assistant florist near her home in Croatia and Laurentiu (15) who is still enjoying school with his friends in Romania.

All four of our guests were accompanied by a family member and a colleague from their national Down's syndrome association. It was invaluable to the POSEIDON team to learn about the kind of technology that would help people with Down's syndrome to become more independent. This information together with the survey the DSA UK conducted with some of our members has really helped to inform the first twelve months of technological development.

In August last year, the POSEIDON project team met in Mainz, Germany. It was a very exciting workshop as we had some prototypes to test. We had a navigation app and an interactive table to work with. As the project is funded by the European Commission, it is vital that the team works with people from across Europe, so once again we invited four people with Down's syndrome to meet with us. They travelled from Switzerland, Luxemburg, Portugal and Ukraine. It was an opportunity for us all to make new friends and try new experiences.

- Damian (22) from Switzerland is an actor and dancer who tours the world with Theatre Hora. Damian speaks three languages fluently and lives at home with his family. When he is not acting or dancing he runs an antique shop.
- Amandine (18) from Luxembourg uses a lot of technology in her everyday life. Amandine regularly uses the Internet (YouTube, Google, Skype, etc.) She also uses an iPhone and her father's tablet.
- Ana (21) from Portugal is a support trainee in a day care centre. Ana has completed professional courses through her job and hopes to do more training. Ana has a very busy social life with her large group of friends.

- Ivan (21) from Ukraine has a job making jewellery which he likes very much as it makes him feel independent. Ivan enjoys travelling, but always makes time for his big passion at home: boxing. He has been boxing for 4 years.

We all worked hard in Mainz. There was a navigation app prototype to try which was programmed to guide our guests with Down's syndrome from the POSEIDON workshop to the Gutenberg Museum on the other side of the city.

The app included photographs showing landmarks along the way to make the journey easier. It worked well as everyone arrived safely at the museum! Our four participants also tried the prototype interactive table which is operated by simple hand movements.

During the group discussions, it was decided that the focus over the next six months will be on apps to assist travelling and the ability to rehearse journeys at home, shopping, general money management and daily scheduling and communication.

The national Down's syndrome associations will each arrange focus groups to meet regularly and give feedback to the developers. We are working with GOODIES at Middlesex University and will keep you posted on our website and blog.

It's very exciting to move into the second year of the project as the technology is taking shape. Keep checking our website and social media for updates on all things POSEIDON!



Using the navigation app to cross the city of Mainz.

POSEIDON
www.poseidon-project.org

Awareness Week

Get Active and Get Involved 16 – 22 March 2015

Each year we target a particular aspect of living with Down's syndrome and this year during awareness week we are campaigning physical activity.

We are busy planning the next Down's Syndrome Awareness Week which is on 16 – 22 March.

This year we are encouraging more children and adults with Down's syndrome to get involved with a new physical activity.

A report in 2010 gave depressing reading where 0% of adults with DS who responded met the recommended levels of activity and only 7.4% of adolescents.

Each person with Down's syndrome should do one hour of exercise each week but it appears that the majority of adults with DS live sedentary lifestyles and there can be problems with obesity even from childhood (see our article on Weight Management page 22).

In the past, one of the difficulties has been the availability of sporting facilities for people with Down's syndrome. The DSA's sports programme, DSAActive has helped to alleviate this problem. There are now 31 football teams across the country that run sessions for children and adults with Down's syndrome and 16 tennis sessions and we are working hard to ensure that DSAActive has a presence in as many regions as possible across the country.

It would be implausible to believe that everyone would like to join in with one of the DSAActive's sporting sessions because we know there will be many who may not be keen on sport, but this does not mean that they don't have to be active. Just going for a walk in the local park every week for one hour, dancing around the house, or walking to the shops instead of getting the bus will help make a difference.

Joining in with a group activity though will not only help fitness and health, it will also help socially and can make a huge difference to the person involved. Children and adults will be able to meet new people and we know that close friendships can develop through these activities. It can also help an individual's personal development. One parent, whose son has been involved in playing

football with DSAActive said that her son's 'self-confidence and social abilities has risen to a level that I didn't even think existed'.

Sheila Heslam, Director of Services said,

"We want this Down's Syndrome Awareness Week to be a celebration of everything active and we are encouraging our members to try something new that could potentially lead to a healthier life. We understand that it might be difficult for some people to join a sports club if it's too far away from home or if they plainly don't like sport, but one hour of exercise a week should be possible for everyone."

"People with Down's syndrome may have many different health issues to deal with but if we can encourage a healthier and fitter way of life then some of these health issues such as diabetes could be avoided."

Football clubs are already getting behind the week with Swindon and Charlton holding special matches and others helping to promote the week or doing collections. In addition, the DSA is holding its annual Big Step Forward on World Down's Syndrome Day in Richmond Park and everyone is welcome to hold their own sponsored walk at a place local to them.

We are putting together a list of activities which you can download from the DSA website or you can receive one in the post if you call the number below. This list should include something that will appeal to everyone, whether that be a new dance class or just walking up and down stairs a few more times a week and we will also include some suggested sports groups across the country.

So this Down's Syndrome Awareness Week we would like to encourage everyone to Get Active and Get Involved.

To get hold of our fundraising and awareness pack please call **0333 1212 300** or for more information about DSAActive look on their website at www.dsactive.org

Help the DSA!

This Awareness Week we need you to Get Active and Get Involved in support of people with Down's syndrome. We have some quick and easy ways for you to raise awareness and vital cash for the DSA's work:

Socks Socks Socks! LOTS OF SOCKS!

Last year hundreds of you took part in the international Lots of Socks campaign and flooded social media with pictures of you, your friends, family and even your pets in brightly coloured socks. This year we think we can do even better!

Our special 'Lots of Socks' socks can be ordered online from www.downs-syndrome.org.uk and all we ask is that you tweet a picture of you in your socks to @DSAInfo using the #Team 21.



Mini collection boxes

Fundraising made simple! We've produced some special edition desk top collection boxes so everyone can get involved. Use yours to collect your 2p and 1p coins (or your £2 and £1 coins!) Take it to school or to work; use it as a swear jar or to collect money from an honesty box tuck shop. We think that £21 is a good target to raise from each box (spot a #Team21 theme there?!). Order yours from the fundraising team now.



The Big Step Forward is a sponsored walk for friends, family and supporters of the DSA and its affiliated groups. It provides the perfect opportunity to get together, raise awareness and vital

funds but more importantly, to have a fantastic afternoon with your friends and family and maybe even make some new ones along the way.

If you are thinking of organising your own walk, get in touch and we can provide you with a 'How To' guide – a simple step by step information pack to help you organise your own walk. Alternatively, just come and join the DSA's official walk on Sunday 22 March in Richmond Park at 1pm where we'll take a gentle stroll around the beautiful Isabella Plantation, try not to get lost and finish off with a group picnic (weather dependent.)

Registration is just £5 per sponsored walker and it's just £2 for additional walkers to get a T-shirt so why not sign up today and make this year's Big Step Forward the biggest yet!

Get your company involved!

It's not just individuals who can take part in the Awareness Week fun – why not get your company involved too?

A bit of office fundraising is great for team spirit. Even if they already have an 'official' partner charity, many companies encourage staff to fundraise for causes that are close to their hearts, and Awareness Week could be the perfect opportunity to introduce your colleagues to work of the DSA.

We can provide special a list of special company fundraising ideas, posters, collection boxes and other merchandise. Contact sarah.terrazas@downs-syndrome.org.uk to discuss your ideas.



Order your Awareness Week pack

You can order this year's awareness week pack in two ways: Sending an email to info@downs-syndrome.org.uk with your name and address or giving us a call on 0333 1212 300.

To order additional fundraising merchandise, please mention what you require in your email or on the phone OR complete the materials order form enclosed in your pack.

Common Sense Tips for Weight Management

By Stuart Mills, Information Officer, DSA



For many years there has been a myth circulating around the inevitability of people with Down's syndrome gaining weight.

Maybe this persists from the bad old days of institutions and hospitals. There are certainly many people with Down's syndrome who defy this stereotype by leading very active and healthy lives. Obesity is not inevitable for people with Down's syndrome.

Having said that, there may be factors that people with Down's syndrome have to overcome that are not necessarily present in the wider population (e.g. lower metabolic rate, less physical activity as a result of lower muscle tone and delayed development and hormonal conditions such as hypothyroidism).

We don't believe that there are any special approaches or interventions for people with Down's syndrome where

weight is concerned. We suspect that, as with the rest of us, prevention is easier than cure.

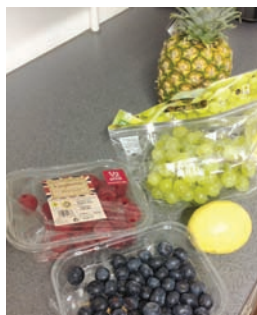
It is easier to lay the foundations for lifelong healthy lifestyles by early education and building on healthy routines than tackling weight issues later in life.

One of the issues raised regularly via our Helpline is one of weight gain when adults leave home and move into more independent living placements. There are no quick fixes in these situations. However, if we are helping children with Down's syndrome to understand healthy living and to enjoy healthy food and exercise from an early age, we can create deep seated routines that hopefully

will be present throughout life. In this way, they may be more likely to be proactive about their diet and lifestyle as young adults when they leave home.

'It's easier to try and avoid her gaining weight than it would be for her to lose weight. My daughter would eat constantly if allowed; she seems to have no switch that tells her when she is full. I keep her active, she swims at least twice a week and she spends huge amounts of time on her swing and trampoline. But obviously as a family we all try to eat sensibly; sitting down for a homemade meal around the table is great for everyone'

'Lots of exercise and small portions – same as the rest of us really'



Vinay makes fresh fruit smoothies

A common misconception is that weight management is all about dieting and losing weight when it is more about managing time, food and activity levels. As with anything, focussing on the positives, rather than a punitive approach, is the best way to go. None of us respond very well to being told what is wrong about us! What can be done rather than what shouldn't be done is the approach that stands the better chance of success.

From an early age all children will benefit from being offered healthy choices; let them feel that they have some control.

We all feel like snacks sometimes; offer your child a choice of fruit or a rice cake for example. Some parents find the use of visual cues around what is healthy versus unhealthy food useful (e.g. grouping foods in a traffic light system). Some adults are very good at knowing when they have had enough 'red' or unhealthy food and stick rigidly to their eating plan as a result of being taught with a 'green' and red' food labelling system.

Children need to be given choice in other areas of their lives too. One of the issues that we sometimes hear about is people leaving home and going wild with unhealthy food shopping because it's the first time they have had a choice and they are taking advantage of new found freedom.

As they grow up, involve your child in planning meals, shopping for ingredients and in preparing meals. An obvious point, but your child will learn from you as a parent so try to model the behaviours that you would like your child to adopt (easier said than done sometimes when the chocolate bar in the cupboard is calling our name!).

Helping your child to recognise when they are full and modelling good portion sizes (e.g. one cup of cereal for breakfast) are good skills for your child to learn. Buying smaller plates and bowls can be a way of making sure that portion sizes are healthy. Regular set mealtimes with the family can help reinforce the lessons

about healthy eating that you want to teach your child.

Exercise – many love it and it makes some of us inwardly groan! The idea of going to a gym would make some of us run a mile in the other direction. The good news is that it doesn't have to look like exercise in the traditional sense; activity is the important part rather than the location. Fun recreational social activities can provide the benefits of exercise without feeling too much like hard work. Building regular family walks with friends into the week can really help. Social activities such as dancing or drama groups can be really good motivators for people with Down's syndrome. Exercise DVDs, particularly those featuring a favourite actor or TV personality, or Wii fitness or Wii workout are enjoyed by many adults.

'My brother has always stayed fairly slim because his whole life he's exercised and I think that's key. You need to find an activity they love and roll with that.'

'My son joined Special Olympics. He attends a session every night of the week. Athletics, golf, basketball, football and dance. Not only helps with his weight but has added so much to his social life'

With the best will in the world, it may be that when your child leaves home and moves into a more independent environment they gain weight. There are no quick and easy fixes in these situations. What seems to work best is small changes to lifestyle consistently applied over time rather than larger unrealistic changes and goals.

Parents tell us that peer mentoring, clubs such as weightwatchers, food diaries and visual timetables with targets can all be useful tools in weight management. There is further advice about weight management when someone leaves home in our resource 'Handling Problems'. This can be downloaded from our website: <http://www.downs-syndrome.org.uk/for-families-and-carers/social-care-support/supported-living/>

'We went to our GP who gave us a free 3 months subscription to Slimmer's world or Weight Watchers. We did not stick to it rigidly but my daughter has lost 2 stone over 12 months and is looking and feeling great. We had tried many different things previous to this but nothing seemed to make a difference.'

'My brother was weighing in at 17st 8lb at the age of 24/25. I decided to take him to my house for a few weeks as I was getting worried about the impact of his weight on his heart. I made sure we had three regular meals a day and that he and I did two sessions a day on the Wii Fit. Within two weeks he had lost weight and felt much better. He's my Champ!'

Final tip:

Learning Disability Nurses can be a great resource to tap into if you have concerns about your child's weight. You can access them via your local Community Learning Disability Team.

Useful DSA Resources

- Healthy Eating (Easy Read)
- Exercise Routine (Easy Read)
- Healthy Eating (Parents & Carers)
- Exercise Routine (Parents & Carers)

Free to download at:

<http://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/healthy-living-guides/>

Other Resources

The Down Syndrome Nutrition Handbook – A Guide To Promoting Healthy Lifestyles by Joan Guthrie Medlen (Woodbine House, 2006)

The Guide to Good Health For Teens and Adults With Down Syndrome by Brian Chicoine & Dennis McGuire (Woodbine House, 2010)

Diet, Weight and Exercise (Easy Read) – Available from Down's Syndrome Scotland (www.dsscotland.org.uk)

Cardiac Disorders in People with Down's Syndrome

Dr Emma Pascall, Dr Liz Marder and Professor Robert Tulloh

The normal heart

People with Down's syndrome have an increased risk of cardiac disorders. These are largely congenital (present from birth) but there is also an increased risk of acquired cardiovascular disease, partly due to other conditions associated with Down's syndrome. Congenital cardiac disorders are present in approximately 40-60 percent of babies born with Down's syndrome. We now know a great deal about these disorders and the Down Syndrome Medical Interest Group, UK and Ireland (DSMIG), has produced guidelines in order that they can be diagnosed and treated promptly. Timely diagnosis and treatment has led to a significant improvement in the health and life expectancy of those affected.

In this article the common congenital heart disorders will be explained in addition to the screening for cardiac conditions as set out by the current DSMIG guidelines. We will then touch on the presentation and treatment of these conditions.

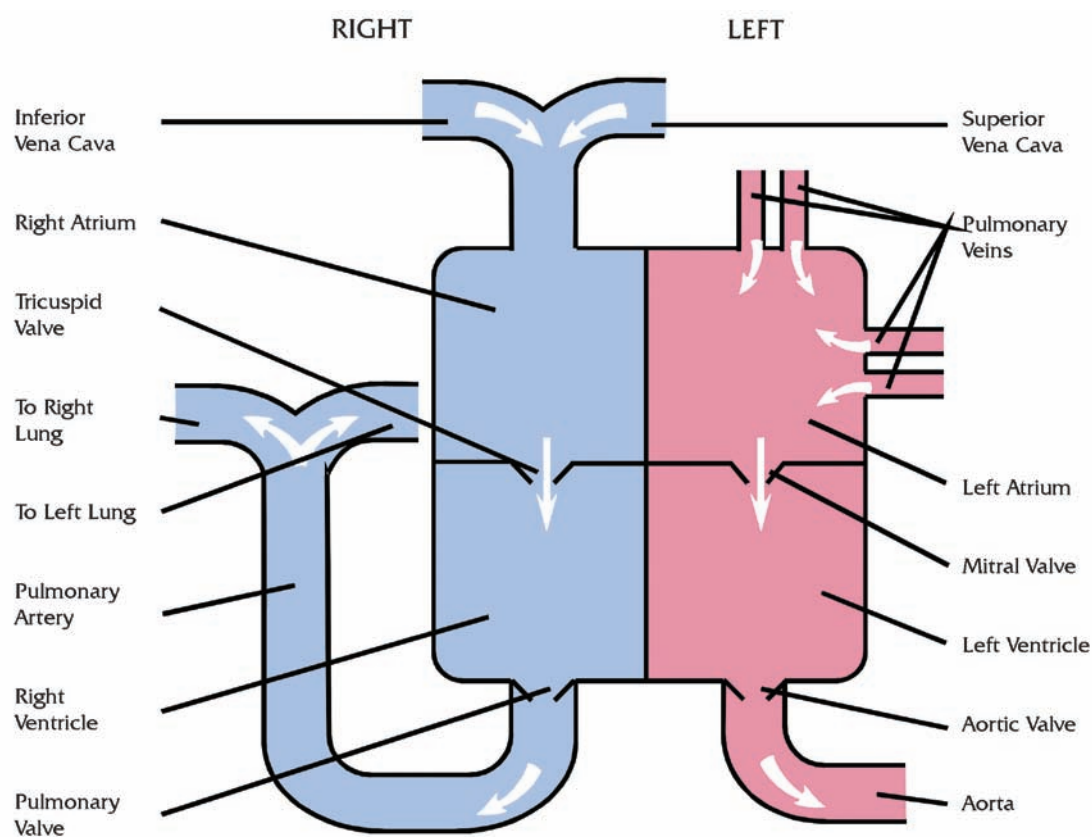
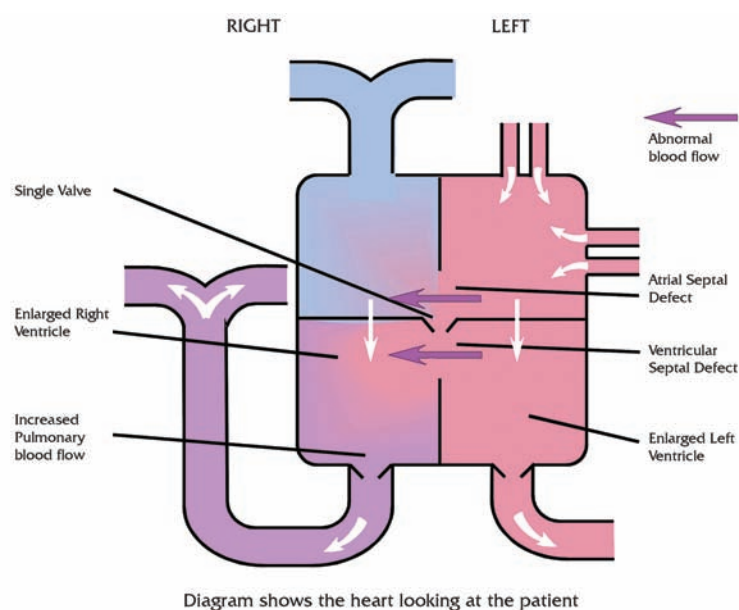


Diagram shows the heart looking at the patient

Which cardiac disorders are most common in people with Down's syndrome?

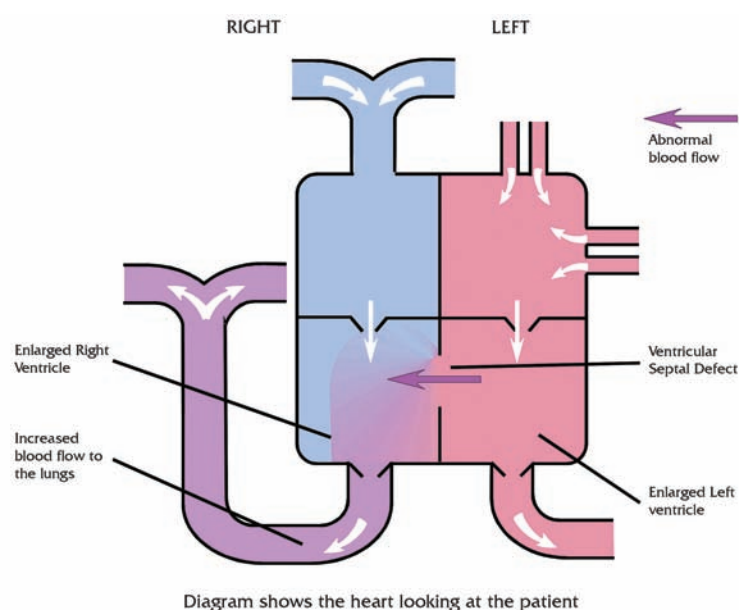
An atrioventricular septal defect (AVSD)

An atrioventricular septal defect (AVSD) is the most common congenital cardiac defect in people with Down's syndrome. An atrioventricular septal defect is when the septum or partition between the two ventricles (lower chambers) of the heart and between the two atria (upper chambers) of the heart does not develop properly and a hole is present. This allows mixing of blood from the left to the right side of the heart causing increased blood flow to the lungs and complications discussed later.



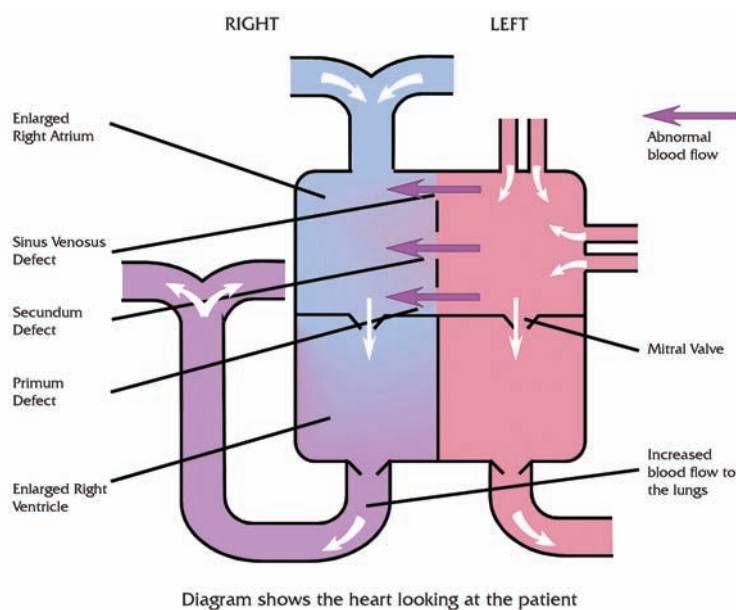
A ventricular septal defect (VSD)

A ventricular septal defect (VSD) is a hole through the part of the septum that separates the two ventricles in the heart. As with AVSD, blood from the left ventricle flows through the hole into the right ventricle but the atria are completely separated.



Secundum atrial septal defects (ASD)

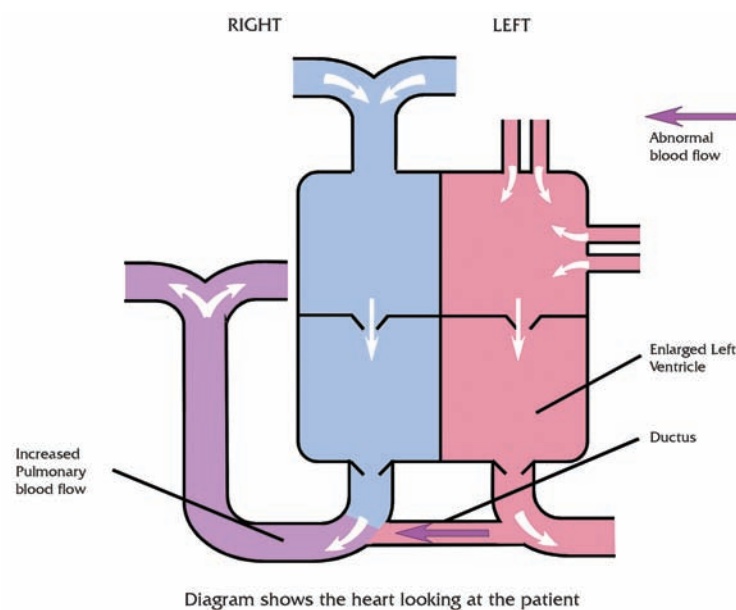
In secundum atrial septal defects (ASD) there is a hole through the septum that separates the two atria, but the ventricles are separate.



Persistent ductus arteriosus (PDA)

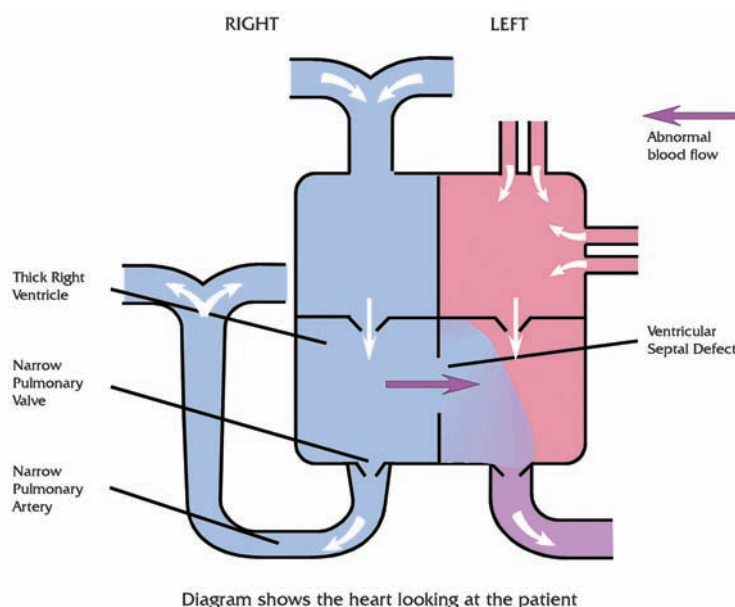
Persistent ductus arteriosus (PDA) is persistence of a blood vessel which is a normal part of the heart structure whilst the baby is still in the womb.

It allows blood to bypass the lungs before the baby needs to breathe, by taking a short cut between the blood vessels that will later take blood to the lungs and the aorta which takes blood to the body. If it does not close, once the baby starts to breathe, the pressure in the aorta makes the blood flow back through this duct causing congestion in the lungs.



Tetralogy of Fallot

Tetralogy of Fallot is another cardiac defect commonly seen in babies with Down's syndrome. The term "tetralogy" comes from the four malformations that occur together: a VSD, an overriding aorta, sub-pulmonary stenosis and right ventricular hypertrophy. The overriding aorta is when the aorta has connections with both the right and left ventricle, (in typical development it only connects with the left). Blood coming from the lungs carrying high levels of oxygen mixes with blood that has just come from the body (deoxygenated), so the blood going around the body carries less oxygen than it should do. There is narrowing of the outflow below the pulmonary valve that separates the right ventricle from the pulmonary artery so the right ventricle has to work harder to overcome this and becomes more muscular and thickened.



Babies with Down's syndrome can also have less common congenital heart defects, or may have complex congenital heart disease with more than one of these problems.

Cardiac problems in older children or adults

Cardiac conditions can also occur later in life. This may include congenital heart defects that were not picked up in infancy (the person may have been born at a time, or in a country where early screening was not available), further problems in those who had defects corrected in infancy, or new problems that may arise.

Investigation of those who have never been screened, or have new symptoms should be by a cardiac specialist.

Symptoms suggestive of a heart problem may include breathing difficulties, fatigue, dizziness or faints, or chest pain. There are of course many other causes of all of these.

Children who had early correction may develop leaky valves or arrhythmias

(irregular heart beat) as a result of scarring. Some may have developed pulmonary hypertension (see below), which will require specialised long-term management including medications.

New problems that may arise include mitral valve prolapse and aortic regurgitation. Mitral valve prolapse is when the mitral valve connecting the left atrium to the left ventricle does not close properly. This valve should close to stop backwards flow of blood as the heart pumps. If it does not close properly blood can leak back into the left atrium causing back pressure on the lungs.

Aortic regurgitation is commonly thought of as a 'leaky' aortic valve. This valve sits where the left ventricle connects to the aorta and usually comprises of three separate leaflets that open to allow blood to flow out of the left ventricle into the aorta to go to the body, and closes to stop backflow of blood from the aorta into the left ventricle. In aortic regurgitation incomplete closure allows blood to flow back into the left ventricle causing volume.

In the general population, as people age the risk of other cardiac problems such as hypertension, and coronary heart disease increases. The same applies for those with Down's syndrome, but rates of both these problems seem to be lower. However people with the syndrome are more likely to be overweight, or have diabetes or thyroid disease, all of which can contribute to cardiac problems. Advice on healthy lifestyles, including good diet, taking exercise, and the avoidance of smoking is as important as for the general population.

Pulmonary arterial hypertension: a complication of congenital heart disorders

The congenital heart disorders seen in children with Down's syndrome can lead to pulmonary arterial hypertension (PAH). This is when the pressure in the pulmonary artery which delivers blood to the lungs is too high.

When there is a hole between the right and left sides of the heart (as in AVSD and VSD) blood can freely move from the left side (which is at higher pressure) to the right side, increasing the blood

in the right ventricle and the blood flow through the pulmonary artery to the lungs. This makes muscle around the pulmonary arteries thicken, and some of the smaller blood vessels in the lung close, so the pressure in the blood vessels in the lungs increases, and blood flow reduces. Increased blood pressure in the lungs causes increased pressure in right side of heart.

Eventually the pressure on the right side equals or exceeds that on the left and blood flows from the right side of the heart to the left through the hole. This means deoxygenated blood (from the right side) mixes with oxygenated blood (from the left-side), and lowers the levels of oxygen in the blood circulating around the body, causing the older child to look blue or cyanotic. This situation is known as Eisenmenger syndrome, and once established will cause increasing health problems, as the child progresses into adult life, and reduced life expectancy.

This situation can be prevented by closure of the cardiac defects at the right time (depending on the type of defect), but not once Eisenmenger syndrome is established.

People with Down's syndrome are more likely to develop PAH than the general population and therefore prompt diagnosis and treatment of these heart conditions is essential.

Sometimes PAH can develop without a major congenital heart defect. The most common cause of this is upper airway obstruction, and this could develop at any stage of life.

When and how are the congenital heart disorders diagnosed?

Currently in the UK pregnant women are offered a detailed ultrasound scan at around 20 weeks' gestation. This may highlight heart defects in the foetus which can then be investigated with more detailed scans (foetal echocardiogram) and may be what leads to the antenatal diagnosis of Down's syndrome. When a diagnosis is made before birth, parents can be offered information about the problem with a plan for care at the time of birth, and subsequent treatment required.

What are the signs and symptoms of heart disease?

It is not always obvious that a baby with Down's syndrome has congenital heart disease as there may be no signs or symptoms. This is why it is so important that they have proper

assessment to check if the heart is healthy or there is a problem that needs treatment.

In some there will be immediate signs such as cyanosis, (blueness of the skin) or they may develop signs of heart failure, with breathing difficulties, or puffiness.

A heart murmur may be detected either during the newborn examination on the first day of life or in later health check-ups. This is an added sound when listening to the heart that we would not normally expect to be there. However some soft murmurs are "innocent" and due to the sound of blood flowing through a healthy young heart.

After the newborn period, signs suggesting heart disease can include faltering growth or signs of heart failure that include poor feeding, and breathing difficulties.

Due to the high prevalence of cardiac disorders in children with Down's syndrome and the potentially difficult diagnosis solely on these clinical signs the current DSMIG guidelines make recommendations that include cardiac assessment and an echocardiogram (heart scan) for all babies born with Down's syndrome within the first few weeks of life.

What is the treatment for these heart conditions?

Treatment will depend on the type of cardiac defect. Some require early surgery, some require treatment with medicines, and may need surgery later, and some may not need any treatment, but require close monitoring in case things change.

A heart specialist will decide on which management is appropriate for each individual child. They will assess the type of defect and the risk of developing PAH and irreversible pulmonary artery disease, and for AVSD early surgery will usually be within the first 3-6 months. If, in other conditions, the pressure in the pulmonary artery is not high, an operation may be carried out at a few years of age with close monitoring until then. Sometimes medical treatment will be required prior to an operation. Such treatment includes nutritional supplementation with high calorie feeds (often via naso-gastric tube) and medication to encourage fluid loss so the lungs are not as congested, breathing is easier and the baby is more comfortable.

Children with congenital heart disorders can be at increased risk of getting chest infections and so it is important to offer all the usual childhood immunizations, as well as influenza vaccine in the winter. They are also more likely to get bronchiolitis caused by the respiratory syncytial virus (RSV) and prophylaxis may be offered to some depending on the heart. Parents should also be offered advice on hygiene and ensuring the child is not around others with infections.

Infective endocarditis

Infective endocarditis is an inflammation of the endocardium (inner lining) of the heart and heart valves. It is caused by bacteria infecting the heart via the blood stream and leads to deposits of clot-like material settling on the endocardium. This can damage the heart valves or the conduction pathways of the heart.

The risk of this infection is higher in people with a known heart problem and is increased by any procedure which allows bacteria to enter the blood stream e.g. surgical or dental procedures.

Up until March 2008 most people with congenital heart defects were given treatment with antibiotics to cover some surgical and dental procedures and prevent infection. However the National Institute of Clinical Effectiveness (NICE) have since changed their guidelines so that only patients with a high risk of getting the infection or where an operation is being carried out where there is a suspected infection are given antibiotic prophylaxis. For people with Down's syndrome who have had isolated ASD, fully repaired VSD or fully repaired PDA, antibiotic prophylaxis is no longer recommended but could still be considered for those with a valve disorder or replacement or who have had infective endocarditis in the past.

Conclusions

People with Down's syndrome are at increased risk of congenital and acquired heart disorders. It is essential that all babies with Down's syndrome are screened for heart defects at a very young age. The possibility of previously undiagnosed congenital disorders or new heart problems having developed, should be considered at regular medical review throughout life. Such vigilance will allow prompt diagnosis and management and lead to a decrease in the burden of cardiac disease in people with Down's syndrome.

References and Resources

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Down's Heart Group
<http://www.dhg.org.uk>

A charity offering support and information relating to heart conditions associated with Down's syndrome

Down Syndrome Medical Interest Group
<http://www.dsmig.org.uk/>
(accessed January 2014)

Website for health professionals on medical aspects of Down syndrome. Includes: Basic medical surveillance essentials for people with Down syndrome – cardiac disease: congenital and acquired. (DSMIG 2007)

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www.dhg.org.uk

The Health Series

The Down's Syndrome Association (DSA) Health Series was launched in October 2013 and covers a range of health and medical conditions written for parents and carers. The authors are professionals and specialists within each field. The DSA answers questions on a range of medical conditions and the titles in this series reflect those most commonly asked about.



All publications in the series are available as downloads from the DSA website:

www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/health-series/

The Down Syndrome Medical Interest Group (DSMIG) have contributed to many of the titles. DSMIG, was launched in 1996 and is a network of healthcare professionals, mainly doctors, from the UK and Republic of Ireland whose aim is to share and disseminate information about the medical aspects of Down syndrome and to promote interest in the specialist management of the syndrome.



The
Down Syndrome
Medical Interest
Group

www.dsmig.org.uk

Titles in the series:

- 1 Ageing and its Consequences
- 2 Alzheimer's Disease
- 3 Bereavement
- 4 Gastrointestinal Problems in Children
- 5 Managing Sleep Problems in Children
- 6 Diabetes
- 7 Eye Problems in Children
- 8 Oral Health Care
- 9 Continuing Pregnancy with a Diagnosis of Down's syndrome
- 10 Depression
- 11 Thyroid Disorder
- 12 Neck Instability
- 13 Epileptic Spasms in Children
- 14 Sexual Health

Shhh... it's the Social Media Report

Undercover with our Shmedia Correspondent Sarah Hoss

Thanks to social media, individuals are increasingly being heard and challenging current thinking. No sooner had I emailed my first article than it all kicked off on social media with the traditional media trailing behind and trying to keep up.

A 34 year old writer took to Twitter on 20 August 2014 to pose a (hypothetical) question:

"I honestly don't know what I would do if I were pregnant with a kid with Down Syndrome. Real ethical dilemma."

This tweet inspired a swift response, from none other than Professor Richard Dawkins, who replied:

"Abort it and try again. It would be immoral to bring it into the world if you have the choice".

And before we knew it, the issue was being raised in phone-ins, (in particular, BBC Radio 4's Any Questions), in The Independent and became the subject for the 'God Spot' on Radio 2.

Richard Dawkins is an ethologist, evolutionary biologist, and writer. He is an emeritus fellow of New College, Oxford, and was the University of Oxford's Professor for Public Understanding of Science from 1995 until 2008.

It was a tad unnerving and also liberating to be able to not just listen in to this digital dialogue but also to participate. The professor was deluged with opposition to the point that he issued a follow-up:

'Those intrepid enough to venture onto my Twitter feed will have noticed a new feeding frenzy yesterday (20th August 2014), for which I apologise'.

I chose to engage by sharing a couple of photos and stating I'd fight til my last breath for my son. Not everyone was so kind, but many parents spoke out in support of their offspring. An American newspaper featured the



@InYourFaceNYer @RichardDawkins @AidanMcCourt I would fight til my last breath for the life of my son. No dilemma.
pic.twitter.com/f7SBS5C2cB

10:10 PM - 20 Aug 14

8,164 views

118 favorites

51 link visits

72 Retweets

story; explaining that polite responses helped win over many.

'They showed him unbelievable grace, and rebuked his words in the most beautiful way imaginable. Using Twitter – the same outlet that Dawkins had to make his opinion known – they explained to him in magnificent imagery exactly why he was wrong.'

(Greeley Tribune)

Thanks to social media, we can all participate in the debate now, which at one time was the preserve of the privileged few who had access to the media and law-makers. Ignoring the very sensitive nature of the subject, how

fantastic is it that we can all stand up and voice our opinions and be heard?

From one little tweet came an outpouring of such support, love and respect for individuals with Down's syndrome.

Those who felt moved to speak out, due to the transparency and immediacy of social media, are helping change the culture.

With every positive message and photograph we are contributing to the sum of human knowledge and in doing so helping to knock down the barriers that held back previous generations and limited life chances.

Effective Complaints

Lesley Black, Information Officer (Education), Down's Syndrome Association

The information officers on the DSA helpline often take calls from people unhappy with the treatment their family member with Down's syndrome has received. This can range from an incident at school to cuts in care services or disability discrimination. We try to advise callers on the correct way to take things further, which might involve a formal complaint.

Understandably people can be reluctant to complain, either because of the effort involved or because they are afraid of making things worse. A well handled complaint, however, can help resolve the problem and may also lead to a change in attitudes and an improved service for others. This article aims to give some general guidelines for making complaints and includes links to sites for specific types of complaints.

First steps – identifying the complaint

This may be clear if you are dealing with a single incident, but for some families it may seem that everything is going awry and they are met with a battle at every turn. Start by thinking about exactly what has gone wrong. This might be something like:

- Discrimination against or other poor treatment of a person with Down's syndrome
- The local authority taking too long to do something like assess a child or provide a service to an adult
- Cuts in services, for example speech and language therapy
- Failure to provide some help that should have been given – e.g. no individual help at school, failure to carry out review of care plan

If you feel you have several grounds for complaint list them separately. You may need to make separate complaints to different bodies or alternatively you may decide to concentrate on one or two issues. See the section on 'Complaints in particular areas' for information on how different types of complaint are handled.

Get the complaints procedure

Once you have identified where you need to take your complaint, ask for a written copy of the complaints procedure. Local authorities, schools and NHS bodies must all have a

published complaints procedure and most service providers will also have one. This may well be available online. Check the following:

- The remit of the complaints procedure. Children's and adults' social care complaints are, for instance, handled differently; there may also be other statutory appeal processes you must use, such as the SEND tribunal.
- Who can complain; this may be restricted to particular categories of people, e.g. the parent of a child, a representative of someone who lacks capacity, a person given permission by an adult service user
- The stages of complaint and their timescales. Most complaints procedures will have an initial informal stage. Before you make a formal complaint it is always worth trying to sort things out amicably first.
- Time limits on complaints – for example for social care and NHS complaints this is within a year. It is generally best to complain as soon as you are able.
- To whom to complain – this will generally be the complaints officer.

Preparing your complaint

It is always best to put your complaint in writing and identify it as a formal complaint.

- **Be clear about:**
 - What happened or failed to happen?
 - When it happened – were there repeated occurrences?
 - Where did it happen?
 - Who was involved?
- Be specific

Vague statements such as 'No one ever gives us any help' 'The school is discriminatory' 'the TA keeps picking on my child' will get you nowhere.

Instead give precise examples e.g. *'The LA took eight months to carry out a child in need assessment'* *'My son was not included in the school Christmas show'* *'The TA wrote in the home-school book that my daughter is stubborn and lazy without checking she had understood the work'*

If you are complaining about a person, then focus on the behaviour and avoid personal insults e.g. *'The practice nurse did not explain the test to my daughter in simple language'*. *'I have not received a reply to my email of ... sent to my SEN caseworker.'*

• Be concise

Use bullet points or short paragraphs with headings. Put yourself in the shoes of the person reading your complaint; can they quickly and easily tell what it's about. It is helpful to provide documentary evidence such as copies of emails, but it will be much clearer if this is attached as an appendix.

• Be polite

... even if you are seething with anger inside

• Outline the consequences

Are you or your family member worse off because of what happened? This might be a specific impact on health or development or it could be upset and distress caused e.g. *'my daughter is now frightened to have a blood test'*, *'my son is becoming frustrated at his difficulty in communicating – this affects his behaviour in school'*, *'cutting my sister's support means she can't go swimming. She is becoming depressed and gaining weight'*.

• Putting things right

Sometimes people complain out of a desire to get even or to make heads roll. For your complaint to be effective, you will need to be clear about the outcomes you want.

Those might be:

- A formal apology
- A particular action to happen e.g. a child to be allowed on a school trip
- A service to be reinstated
- Staff training – for instance on Down's syndrome or equality legislation
- A change in policy or procedures

• Get help

See the links below for more information. If you are not sure how to take things forward, ring or email the DSA helpline and we can point you in the right direction. If your complaint is about something like cuts in services it may help to join together with other families. Contact your local support group to see if others share the same issues.

Complaints in particular areas

Education

All schools must have a published complaints procedure. If your complaint relates to a special educational needs or disability issue, check your LA's local offer for information about disagreement resolution and complaints. If your complaint is about a statement or an Education Health or Care Plan, you

may have access to formal mediation or appeal to tribunal

Ofsted cannot take on complaints related to individual children but may intervene on matters affecting the whole school.

You can find more help from the following sites:

- www.gov.uk/complain-about-school
- www.ipsea.org.uk/what-you-need-to-know/challenging-decisions

Social care

There are different procedures for children and adults:

- Children – 3 stage procedure
- Adults – local resolution within one day then formal investigation

Guidance on children's social care complaints:

www.gov.uk/government/publications/childrens-social-care-getting-the-best-from-complaints

Healthwatch England has information on complaints on social care and health and links to letter templates from Citizens' Advice:

www.healthwatch.co.uk/complaints/guides

Health

The complaints process for NHS bodies is similar to adult social care and is governed by the same regulations. See Healthwatch England above for more information. You may be able to get help from the NHS Complaints Advocacy Service:

<http://nhscomplaintsadvocacy.org/>

The Parliamentary and Health Service Ombudsman has resources on health complaints for people with learning disabilities as part of their 'Complain for Change' campaign:

www.ombudsman.org.uk/complain-for-change

Taking things further

If you have made a complaint to your local authority or an NHS body and you are not happy with the outcome, you can ask an Ombudsman to investigate.

- Local authority complaints and complaints about adult social care providers – the Local Government Ombudsman (LGO) www.lgo.org.uk
- NHS complaints – the Parliamentary and Health Service Ombudsman (PHSO) www.ombudsman.org.uk

George Karol Armour

We have read so many stories of the feelings parents have when they find out for the first time their child has, or may have Down's syndrome.

Our experience differs no less. However, we would like to say that within the short time George Jnr has been with us, we cannot be any more in love with our wonderful baby. We cannot help feeling that our lives from now on are going to be filled with challenges and maybe some tough times, but certainly a lot of love, happiness and laughter.

We would especially like to thank our family, friends and work colleagues and have been overwhelmed by some of their reactions and messages to our special news.

Most have been positive, encouraging and all have expressed their love and look forward to meeting little Georgie.

Finally we are grateful to the DSA who have been supportive, welcoming and encouraging and for allowing us through this magazine to celebrate the birth and life of our Son George (Jnr) Karol Armour who came into this world on 4 November 2014.

Mum, Dad and Weronika love you very much.

Photographs by George and Gosia Armour.



Life as a Mum

Sara Porter

I am currently writing this article with my little nine month old baby on my lap. I am very tempted to move her, however I know that Kara may wake up and then there will be no chance to write. Its been a productive morning with a wash outside and hoovering done. I know that once my eldest daughter returns back from preschool I am going to have chaos and so should just enjoy five minutes peace. I am returning back to work tomorrow and have all my clothes and books packed ready for using my brain after my maternity leave.

The only difference between myself and the thousands of other mums who will read this and go, yes I know this scenario, is that Kara has Down's syndrome. I am also one of the few women who had the prenatal test and found out that Kara had Down's syndrome. It's one of those scenarios that you pray will never happen. I certainly was not that old at the time, being 37, and this was my second child. I was rather blasé about the whole process and was more worried about the five blood samples that you have to give. I am not great with needles and you do feel like a human pincushion during pregnancy.

I think our first inkling that there might be an issue was at the 12 week scan when the radiographer asked us to go for a walk so she could see the baby more. We were then seen by two further radiographers and this time it was a formal occasion and they were looking for something. Normally there is a sense of joy – but these health professionals were giving nothing away.

Later on that month I was out for a meal for the first time in ages. The morning sickness had subsided and I felt like a human being. I remember sitting down waiting for my glamorous friend and there was a call on my mobile. It was the fetal midwives team suggesting that I needed to go in and talk to them. My close friend asked if I needed to go home and I said no – no I have not felt like eating for three months and I am going to have a meal.

The next day we were told the results, that we had a 1 in 5 chance of having a



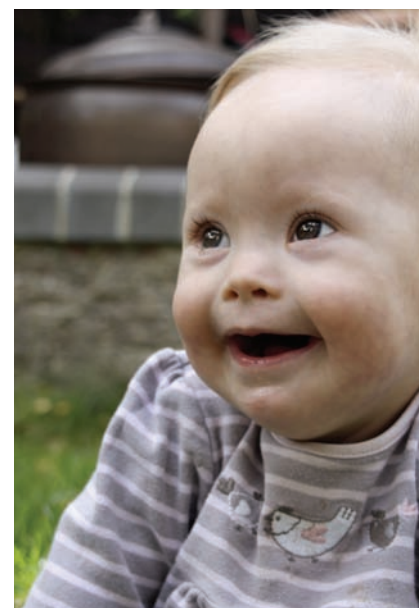
baby with Down's syndrome. I remember thinking what, why and what next. It was like a death – that feeling of such total grief. We were counselled on our option and I decided to go for an amniocentesis – I needed to know either way. I then remember going to the hospital for the scan and then the needle going in. It did not hurt really and anything compared to child birth is painless. We got the results – it was positive. We had options – lots of options but they were not without a cost. There was no pressure from anyone. I asked relevant people – people who had children with DS. I read so many papers and literature, as whatever decision we made would have a huge impact.

We had so many scans that I felt I could have set up a little bed at the fetal medicine team. Sometimes the scans gave us good news and other times we found out that Kara could have needed heart surgery. We were treated with kindness and respect from the team at Derby and only ever had one incident at another hospital that caused us pain.

The pregnancy was a good one and the birth was quick. It was my daughter's third birthday party and straight after I went into labour. And Kara was born. The reality is so much better than anything I ever dreamed of. Kara had no surgery, no feeding issues and really no health worries. She is hitting all her milestones and I have breastfed her since birth. She is almost crawling and weaning very well. She is on no medication and

is a very lovely daughter. Eloise my eldest I think adores her but as she is a baby I think like any other three year old she finds her a bit boring. Our new house is much more interesting.

We are now off to see a friend – and pick up Eloise from nursery where Kara will start in a month – which is a huge milestone. For my Kara has been such a blessing and I feel so happy as she has enhanced our family. I have also just started doing talks to student health visitors so they get an idea of just how very normal life is with a child with DS.



A Pilgrimage to Santiago with my Sister

By Cory Novis

Every year thousands of people from all around Europe make a pilgrimage to Santiago De Compostela, the capital of Galicia in northwest Spain, to follow in the footsteps of Catholic pilgrims who have been traveling to the Cathedral in Santiago since medieval times.



This summer my family took the week-long hike for 120 kilometres along the 'Camino Ingles' (the 'English Way') with up to 14 kg of weight on our backs. This is quite a hike for most people, as I can say from experience, but for none among us was it harder at times than for my younger sister Vivian, a thirteen year old girl with Down's syndrome. Far from being a hindrance, however, my sister proved to be somewhat of an inspiration.

We averaged just over 17 kilometres a day and we hiked no matter what the weather, through both heavy rain and the searing heat of Siesta. We had to push ourselves just to get a place to sleep at one of the 'albergues' or 'hostels' set up, with rather limited spaces, to house pilgrims on their way to the Cathedral. To handle challenges like this people need to understand why they are doing them and what they are aiming for. Personally, I made sure to keep my mind on the big white mattress and large dinner that awaited me at the next albergue and the awe inspiring sight of the Cathedral that was our ultimate goal.

Viktor Frankel, an Austrian psychiatrist and neurologist, said about suffering that *"Those who have a 'why' to live, can bear with almost any 'how'."* Although I wasn't faced with the drastic life or death scenario of this quote, I still found that knowing why I was challenging myself helped me to face the task. Maybe it's just natural bias which makes us assume that those with disabilities won't perform on par with others at



physical challenges, or perhaps we assume that a lack of understanding would mean a lack of motivation. By the latter I mean to say that perhaps we assume that those with disabilities can't really give meaning to suffering and, thus, find it harder to endure. But I can say for certain, my sister had a 'why'.

Every day my mother would explain to Vivian exactly where it was we were going to and how far it was until we got there. My sister would often ask about the upcoming hostel and about meals. We would then remind her about the name of the upcoming town where we would find both of these things and throughout the day, when Vivian seemed tired, we would remind her about Neda or Ponta Deume or Betanzos and she would brighten up instantly. Just like me, my sister was looking forward to that big white mattress and large dinner and it helped her to carry on.

If you're still not satisfied allow me to give you another example. My mother would also talk to my sister about suffering in regards to Christianity and how *"Jesus suffered for us and so now we were suffering a bit for Jesus."* A relatively abstract concept (and not one I'm pressing anyone to believe), and yet it seemed to work, my sister would bravely soldier on despite her aching feet and sore shoulders. You don't need to believe in Christianity to appreciate that it seemed to give my sister a 'why' for her suffering and in that way make it more bearable.

What I ultimately learned from this experience is this: facing challenges and dealing with suffering by giving yourself a 'why' is possible for almost anybody, even for my little sister Vivian. In this way, whenever we need to deal with problems in our daily lives, we need to remember what it is we are working towards: achieving our goals, supporting our families, making the world a better place or even just that feeling of release that comes with lying down to sleep after a long day of hard work and challenges.

p34: Vivian on the Camino. p35: Cory, Cate (Vivian's mother), Vivian and Kenny her other brother.



Recruiting Care Staff

Peter Wood

Many of us find interviewing potential carers to be daunting. It's not something we do every day, and it's the main opportunity for both interviewer and interviewee to find out something about each other. We need to plan it carefully, otherwise there's a danger that our minds will go blank in the interview and we won't finish the session with the information we need. Here are some hints and tips, based around a technique called Behavioural Interviewing.

We should start by writing a Job Description. This is a list of the tasks and responsibilities of the role. This should perhaps cover two pages. If we have written just one line – *"look after my child"* – then we need to break that down. If we have written 10 pages, then that's too much.

Once we have our list of tasks and responsibilities, we can start to work out some questions, and write them down. What we are looking for is evidence that the interviewee has experience in doing what we need.

Here is an example. If our child is doubly incontinent, then nature will take its course. If we are out and about, then with luck there will be a disabled toilet nearby that's big enough to lie down for a change. If there's no toilet, then it's an al-fresco experience, for both small person and carer.

So, our Job Description has got *"changing nappies/pads"* on it. We could ask the candidate *"Do you have experience of changing nappies when out and about?"*, they'll answer *"yes"* and that's the end of it. That was a closed question and we have learned almost nothing.

But, if we have planned our questions, we can ask *"Tell me about some occasions when you've been out with a client and needed to make a nappy change"*. And then wait for the answer. In this case we are looking for an answer that includes not only mechanics but also things like dignity, self-respect and improvisation, and quite possibly a sense of humour!

An additional useful step in preparing for the recruitment 'campaign' is to write a Person Specification as well as the Job Description. What sort of person is

needed to do this job? What sort of experience and qualifications do we think that they need? For example, do we want them to have a first-aid certificate, or are we willing to do without or to pay for the training ourselves if required? If they're driving our child about, do they need to own a car, have a clean-ish license and be able to show us an insurance certificate showing that they're insured when on their employer's business?

What experience do we want them to have had? Will we take a relatively inexperienced school leaver (and train them ourselves) or do we want so many years' experience of special needs? Would we prefer someone who is a level-2 TA at a Special School? Are we giving them responsibility over budget and money? If so, can they demonstrate that they've done this before...? And so on. Thinking about these things beforehand will give us some more questions to add to our list.

Along with preparation, waiting for the answer is the other great secret of interviewing. Never jump in and fill silences. Give the interviewee time to think. It's not a comfortable, cosy chat, so don't try to make it into one. We must never be hostile (remember that the candidate also has to come out thinking that they want to work for us) but we must be firm and not let the interview turn into just a pleasant conversation. We decided beforehand what questions we need answered, so we ask the questions and wait for the answers. If the candidate takes a long time to think about their answer, then just shut up and let them! Don't be embarrassed.

If our questions are reasonable, and they can't answer them to our satisfaction, then both we and they know that they're not the candidate for the job. If we do it

well, then even if the candidate doesn't have the skills we're looking for, both we and they will exit the interview feeling that they had a fair crack at demonstrating what they know, and that the interview was fair. If we just have a cosy chat, then the candidate can rightly complain that they weren't given the chance to demonstrate what they know.

We must make notes during the interview otherwise we will forget key points. We should have our questions in front of us, written down, and make notes of the answers as we go. The candidate won't mind the gaps and silences as we write. They're there to answer our questions so they'll wait.

We should be clear at the start of the interview about how long it will take, and then be mindful of the time, and keep control of the discussion so that we get to the end with answers to all of our questions.

Always turn the tables at the end of the interview. We must give the candidate chance to ask questions, and we must answer them clearly, in the same way that we expected the candidate to answer our questions. We don't look at the clock and say *"time's up, must be going"*. Remember, they want to know if they can work with us too.

We must always remember to thank the candidate for coming, and to thank them for their time and interest. We should also be careful not to say anything at this stage that would lead them to believe that they have the job. We need to see everyone, and compare their skills and experience.

Try not to do the interviews at home. We have a vulnerable child at home – so we don't want random strangers walking in – and we have too many distractions.

Organise childcare and rent a room. For example, in some areas local libraries rent rooms at very reasonable rates.

Once we've done our interviewing and have our preferred candidate, that may well be the time to invite them back home to meet our child and see how they get on. We could give them a short description of our child, and ask them to bring some sort of activity with them that they think might be popular, and then watch how they interact.

When writing our Job Description, we should have given some thought to the design of the job. This is a whole

separate topic, but we can perhaps summarise by saying that we should try to give people a job that they want to do, that will interest or excite them, and that they will want to keep doing. We are, after all, trying to pick people who will stay with us for the long haul, who are in some ways "surrogate family" for our children. We are probably also planning to leave our child in the sole charge of this carer, so we want them to care very deeply about that responsibility, not to be someone who's frustrated, fed-up, distracted and uncaring.

There are a few basic things that we can do when designing the job. We

should try to give the carer enough regular hours so that they feel that they are forming a relationship with our child, and so they get some satisfaction from seeing progress. Most people enjoy learning new skills, so perhaps try to give them training and / or involve them in therapy sessions (which is a good way of getting training for free).

If we get this right, then we can hopefully find carers who will stay with our family for several years, which is ideal for everyone.

Peter Wood is a parent of a son with Down's syndrome.



Time for your Child's Preschool?

How we found the right one for our son and the importance of paving the way

By Angela and Neil Frisby



Austin

We would like to introduce you to Austin our son who has Downs Syndrome. Austin aged 3.5 years has gone from strength to strength with a bursting personality and character of steel, he is our little superman. We wanted to share our positivity with the aim to encourage other parents starting their journey in finding a preschool setting. Children with Down's syndrome have different health and learning needs like all children, however it must be said for all the hard work that goes in, the rewards will hopefully be as plentiful as ours. We have seen our little boy grow and develop in ways we could only hope for once upon a time.

Paving the way

We soon became advocates of the phrase 'early intervention'. We cannot express enough how important this time is! A slow constant drip of fun learning to be soaked up like a sponge, is without doubt one of the best things we did for Austin.

We were introduced to Surrey Portage around Austin's first birthday, a regular home visiting educational service for preschool children with special needs.



Austin's portage teacher was great not just for Austin but Mum and Dad too. We learnt to break everyday tasks into smaller steps. She helped with the transition into nursery, highlighting any particular strengths alongside target areas to develop.

When Austin was ready we joined an early development group held at a Surrey Children's Centre. The group was for Portage children with Down's syndrome and their parent/s, to develop the child's early learning and language skills through play. It also provided an opportunity to meet other parents and help the children prepare for nursery. The group was held by two experienced and welcoming portage teachers. As parents we shared information, Makaton and tips such as story books you can create yourself based on daily routines at home, out and about or going to preschool.

Our Search

The amount and method of Special Educational Needs (SEN) provision offered by each preschool setting differed greatly and there was no magical database (we found) for mainstream preschool settings with experience of children without Down's syndrome. We got hung up on the fact hardly any setting seemed to have had children with Down's syndrome to offer the experience we were counting on for reassurance at the time. In the end we realised we must look at which other important factors were on offer. The best advice we can give is to literally visit as many nursery settings as you can. It would be unfair to suggest the next statement is the case entirely, but on our personal search we found the mainstream preschools that already had children with SEN attending regularly, were already carrying out relevant processes and procedures whilst providing appropriate support in connection to the child's needs on a daily basis. This gave us as parents huge reassurance and confidence in those early days. It goes without saying all the nurseries we visited were very welcoming, understanding and supportive. We found we needed to weigh up their want to commit with the actual environment, SEN provision on offer and overall experience.

Welcome to Austin's Mainstream Preschool: Springtime Nursery School and Day Nursery in Staines

Austin's preschool have been amazing. He has a really fantastic relationship with his key person and all the team. There are over ten children with different special educational needs in this mainstream environment and none have Down's syndrome. We have seen a lot of effort

and time put in to settling Austin, which we feel played a huge part in his positive development to date. Springtime Nursery School will now provide information and clarity from a preschool perspective such as what is an ISP and discretionary funding, the roles of the Special Educational Needs Co-ordinator, the Key Person and Nursery Manager.

Pippa Spink, Early Years Professional writes:

At Springtime Nursery School and Day Nursery in Staines we pride ourselves on the way we support children and families including those with a range of additional needs. When we meet a child like Austin we talk to the parents and professionals who know him best so we can assess how to help him be involved in all the activities and learning opportunities within our setting.

As Nursery Manager I am responsible for overseeing the smooth running of the nursery to ensure all the children attending have the opportunity to achieve the best outcomes possible. Much of this involves working collaboratively with parents and practitioners both within the setting and relevant outside agencies. By delegating responsibilities we have an effective management team who all have clear roles in order to make this happen including the Special Educational Needs Co-ordinator (SENCO).

The SENCO helps those staff working in the rooms with the children to meet Austin's educational and physical needs using recommendations from his parents and professionals who see Austin regularly. For each child this is different so an Individual Support Plan (ISP) is drawn up for parents and practitioners to follow as part of Austin's daily routine. This way we can all check that Austin is making good progress in important areas of development like communication, language and play skills. The SENCO will also use these plans as evidence for the need to claim for discretionary funding from the County Council's allocated budget. If funding is agreed we are able to recruit an additional member of staff to support the group and provide some one-to-one time for part of the session. By careful organisation of well qualified and experienced practitioners we aim to help every child become confident able individuals in readiness for their school lives.

In Austin's case we were able to assign Daniel, Austin's key person to work closely alongside Austin for much of the session. Like all 'key persons', Daniel's role is to know Austin well and practice games and tasks on the ISP in fun ways

throughout the session. This way Austin can play with the wide range of resources available with a supporting adult and have some structured one-to-one time to practice specific skills. Now Austin is ready to progress from the 2-3 year old class to the 3-5 year class. We have continued to apply for discretionary funding to pay someone to maintain this high level of direction and support, deciding that due to the special bond that Daniel has already established with Austin, he would do this initially while Austin becomes familiar with the new team of staff.

When looking for a nursery or pre-school, viewing lots of settings is good advice. Each childcare provider is different so asking to look around and talking to staff will help you decide what each has to offer your child and how the local authority can help. Every county council operates differently so in Surrey we are fortunate to currently have an Early Years Improvement Advisor who offers us guidance on a range of information from teaching strategies to funding additional staff. You could look at your local authority website to see what is available under the new local offer:

"Following the introduction of the Children and Families Act (2014) AND the SEND Code of Practice (2014), local authorities are required to publish and keep under review information from services that are available for children and young people with SEND (Special Educational Needs and Disability) aged 0-25. The intention of this local offer is to improve choice and transparency for families. From the Local Offer, parents and carers will know what they can reasonably expect in their local area"

<http://www.surreycc.gov.uk/learning/early-years-and-childcare-service/early-years-practitioners-and-providers/special-educational-needs-and-disabilities-in-early-years>

Conclusion

We as parents really feel we hit the jackpot with Springtime Nursery School and Day Nursery. Austin is happy going in and coming out, he loves going to preschool. The entire team is on board, really welcoming, supportive and friendly which makes such a difference not only for the child but the parent/s too. The feeling we can approach with questions and share thoughts or ideas has been crucial to us. It is clear the children's needs are put first in conjunction with involving and updating the parent/s. We would like to take this opportunity to say a huge thank you. We found courage through this journey which is what we sincerely hope this article gives you.

Local Group: PSDS in Surrey

By Helen Shiers



providing support
for children with
down syndrome
and their families

www.psds.info

registered charity number 1123079

PSDS was founded in 2006 by three families who all had a child with Down's syndrome born within a year of each other. What started as coffee mornings, where parents could share their experiences and the children could play together, quickly grew in to something very special and, early in 2008, PSDS became a registered charity (and subsequently became affiliated to the national organisation, the Down's Syndrome Association).

Our principal goal is to provide support for children with Down's syndrome and their families. We meet regularly as families to share our experiences and provide a network of support, friendship, advice and expertise. This benefits not only our children with Down's syndrome, but also their siblings, ourselves as parents and all family members.

At the first "official" PSDS gathering, 7 families attended with their children. Now, 8 years later, over 50 families benefit from the services provided by PSDS, including:

- weekly pre-school early development groups (*DIGBIES Developing Individual Growth By Imaginative play, Education and Speech*)
- speech and language therapy
- music therapy
- occupational therapy
- sing and sign sessions
- educational conferences
- school support scheme
- teacher and teaching assistant training programmes
- after-school drama clubs
- monthly family coffee mornings and play sessions
- social events including a summer family picnic and Christmas party
- access to a special library of resources

Our aim today is exactly the same as when PSDS first started – to help children with Down's syndrome reach their full, wonderful potential.



Two of our children at DIGBIES (our early development group) enjoying their learning activity

We want children with Down's syndrome to have access to opportunities available to all others and for there to be no pre-conceived ceiling on what any of our children are expected to achieve.

Down's syndrome is just a part of who our children are, not what they are. We want people to see beyond an outdated and often misunderstood label, focus on the enormous potential of individuals with Down's syndrome and remember that, most importantly, we are all unique and different from

each other – regardless of whether or not we have an extra chromosome!

As a charity we are proactive in our efforts to challenge and change perceptions. Our membership includes families who have been featured in local and national media, including numerous press articles, magazine features and interviews on radio and television. We have active bloggers within PSDS who are reaching out and connecting with families across the globe, sharing their experiences and offering encouragement,

inspiration and advice. We are also delighted that some of the children within PSDS have had the opportunity to take part in major advertising campaigns, appearing in a TV commercial for a well-known supermarket, as well as modelling some of the latest children's fashions in clothing catalogues.

Being given a platform from which to raise positive awareness in the media spotlight is fantastic, but we are just as proud of all that every single one of our children achieves on a day-to-day basis, whether it's earning badges and awards within the clubs they attend, receiving praise and rewards from school or taking part in activities alongside their siblings and peers. Every day, in so many different ways, our children are helping to raise expectations and inspire others.

As a parent-led charity, our key aims are:

- to provide a stimulating and caring environment in which our children can have fun and develop self-confidence
- to provide a network of support for parents, siblings and children with Down's syndrome at each step on their challenging but rewarding journey
- to ensure that our children receive maximum input in all key areas of development
- to assist and support families coming to terms with the news that their child has Down's syndrome
- to aid professionals in understanding the more practical issues which need to be addressed when assisting a family which has a child with Down's syndrome
- to see the potential in all of our children and celebrate their success

With an expanding membership and a widening age range (at present, the youngest child within PSDS who has Down's syndrome is 6 months old and the oldest is 11 years old), it is important for us to continually review our offering – and look ahead to the future stages of our children's development.

We offer excellent support for babies, pre-schoolers and children of primary school age and work hard to ensure that we continue to offer the very best services for children and their families within this age range. In addition, we have turned our strategic focus to devising services and support to benefit children moving on to secondary school, young adults in further education and individuals moving towards living and working within their local communities.



Top: PSDS receiving a cheque from Reigate Priory Hockey club at our Summer Fun Day in June 2014
Bottom: PSDS with their cheque from Leatherhead Rotary. This photo was taken at Fishers farm park Sussex on our annual summer day out for families which we fund.

This is an incredibly challenging but exciting time for PSDS as we look to expand our offering and as our membership grows.

It also means our funds are under immense pressure. We have recently expanded our after-school drama club, our pre-school early development groups (DIGBIES) and our school support service – which in turn will increase our annual fundraising target to approximately £80,000.

We are well supported by members and friends doing events such as marathons, cake sales, climbing

mountains and many other exciting things! We also hold our own events such as an annual Fun Day, wine tasting and in November 2014 held a very successful Quiz Night.

We receive support from local Round Tables, Rotary and Lions clubs and make funding applications to various organisations. We are immensely grateful to all who support us and every penny we raise goes towards helping our families.

For further information please do look at our recently revamped website at www.psd.info or email sarah@psd.info or Helen@psd.info.

Educating Learners with Down Syndrome

Research, theory and practice with children and adolescents

Edited by Rhonda Faragher and Barbara Clarke. Routledge. 2013.

Review by Carol Allen

The preface to this book states the editors' reason for gathering and presenting this interesting and useful collection.

"For individuals with Down Syndrome, the extent of the effect of intellectual disability depends largely on the degree of provision of appropriate support and intervention."

The editors focus on the school years, but to do so without reference to life-long learning would be a huge loss and so it is very useful to have these years contextualised with reference both to work and support in the early years and the impact of what follows in the field of post-school provision.

Faragher and Clarke's particular area of expertise is shown in Part 11, however this book offers a balanced collection of expertise collated into three sections:

- Part 1: Issues in learning and teaching
- Part 11: Learning mathematics
- Part 111: Literacy development

Each chapter gathers together a wide range of research and presents it within a context of inclusive, assessment-based practice, thus offering the reader a cogent analysis of current ideas and the underlying research with which to illuminate their own practice. It is this final point that is so interesting, the reader is able to dip in to chapters of choice and pick up new ideas; challenge or corroborate their current practice and follow up particular lines of research around a topic as the collation is presented for future reference.

The clear link between research and practice underlies every stage of this book. The stronger chapters offer exemplification of an issue, linked to the appropriate research and often shown as a quick and simple example concerning one child and a classroom moment. This allows a direct link from research to intervention or vice versa ... extremely useful both for an educator new to the field, in addition to those who have worked for longer in this area.

By constructing the Prologue from a selection of brief insights written, dictated or constructed by, and about, people with Down's syndrome themselves the scene was set perfectly, reminding us that to achieve educational success there needs to be a triad of collaboration between parents/carers, education and the student themselves.

Effective educational provision must move from a 'done to' approach to a 'achieved with' working ethos.

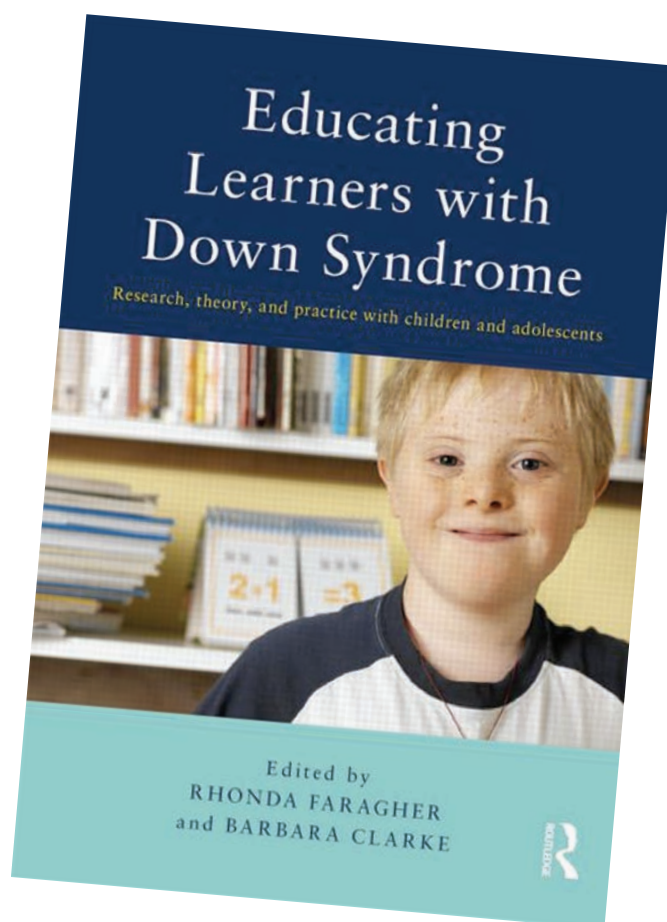
Of particular interest were the two chapters which discussed provision, opportunity and attitudes/expectations for children born with Down's syndrome in Indonesia as they illuminated the difference between those countries still identified as, 'developing,' and those which have been addressing these specific areas for children with additional needs for longer.

The two key barriers which were identified as initial areas to address were:

- the negative attitude towards disabilities
- policy versus implementation

Whilst reading through this book it seems that in point of fact these hold true, not just for developing countries, but to greater and lesser extents often form the barriers to be found in many places throughout the world.

There are so many policies that exist that do not translate into practice, there are so many who still need to embrace the opportunities and excitement that this field of education offers. This book does well to remind us that all is not perfect in our own practice, that there is still much to challenge, to improve and to work on. What is even better, it offers solutions, ideas and a positive way forward. It is not just Indonesia that needs to continue this journey!



Carol Allen is School Improvement Advisor (ICT and SEN), Children, Young People and Learning, Early Years and School Improvement Service, North Tyneside City Learning Centre

Looking Up

Cornwall Downs Syndrome Support group are very proud to publish their Looking Up book.

Each page of the book shows the ordinary 'extraordinary' journey of some of their members from birth to childhood. The book will be given to all new parents born in the county.

New parents will be able to identify with the pictures of the babies after surgery or with NG (nasogastric) tubes but will see that the children can grow up to do ordinary and extra ordinary things.

The book also has pictures of the wonderful T21 exhibition which has been shown locally in Cornwall in the hospital and in Westminster for a week earlier last year. The photos, taken by Simon Burt Photography, aim to show the personality of the child or young person before the condition and he has achieved this wonderfully.

The book will be available on Amazon shortly.



KEEP CALM

Show your support and join the Keep Calm Gang by wearing one of our fantastic new T-shirts.

Children's T-shirts are available in sizes:

3-4 years (W76cm x L43cm)
5-6 years (W79cm x L48 cm)
9-11 years (W88cm x L59cm)

Adult T-shirts are available in sizes:

Smal, Medium, Large, XL

Colour: Red

Children's t-shirts cost £8 plus £2 postage
Adult's t-shirts cost £10 plus £2 postage

To order:

Call: 0333 1212 300 and ask to speak to Fundraising.
Email: info@downs-syndrome.org.uk
Online: www.downs-syndrome.org.uk
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www.langdondowncentre.org.uk



Down's Heart Group
Tel: 0844 288 4800
info@dhg.org.uk
www.dhg.org.uk



www.poseidon-project.org



The
Down Syndrome
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Group

www.dsmig.org.uk



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Vice Chair	Sarah Leggat
Treasurer	Sandy Lawrence
Chief Executive	Carol Boys

The following can be contacted
through our National Office
on 0333 1212 300

Getting Support: Information Helpline

We are happy to answer any query, no matter how small via email info@downs-syndrome.org.uk

Our Information Officers are available to answer calls Monday-Friday 10am-4pm. They can give advice about any aspect of living with Down's syndrome, from medical enquiries to support services to behavioural issues. They work with our team of advisers to offer advice on any specialist areas.

Local Parent Support Groups

The DSA has details for local parent support groups across the UK. For details of your nearest group, please see our website or contact our national office.

Training/Conferences

Booking Enquiries
E-mail: training@downs-syndrome.org.uk

National Office

Langdon Down Centre
2a Langdon Park
Teddington
Middlesex TW11 9PS

Tel: 0333 1212 300
Fax: 020 8614 5127

E-mail: info@downs-syndrome.org.uk
Website: www.downs-syndrome.org.uk

National Office hours are Monday-Friday 9am-5pm. Emergency numbers outside office hours are given by recorded message.

Regional Offices

WALES

Tel: 0333 1212 300.

NORTHERN IRELAND

Unit 2
Marlborough House
348 Lisburn Road
Belfast BT9 6GH
Tel: 02890 665260
Fax: 02890 667674

Office hours Mon-Fri 9am-5pm



Down's
Syndrome
Scotland

helping people realise their potential

SCOTLAND

is covered by its own association. For more information contact:
Down's Syndrome Scotland
158-160 Balgreen Road
Edinburgh EH11 3AU
Tel: 0131 313 4225

REPUBLIC OF IRELAND

is covered by its own association. For more information contact:
Down's Syndrome Ireland
Citylink Business Park
Old Naas Road
Dublin 12
Tel: 01 426 6500
Fax: 01 426 6501
Email: info@downsyndrome.ie
Website: www.downsyndrome.ie



www.ds-int.org

If you are based outside the UK and are looking for local support please contact Down Syndrome International, an international network of individuals and organisations.