

journal



Photographic Competition • SEN Legislation
Photographing Prisca • Neck Instability
Claiming ESA • Mental Capacity Act
Local Government Ombudsman
Using a Smartphone • Our Members Stories

Letter from the Chief Executive



Carol Boys

As usual, our Journal is packed full of articles and information for people with Down's syndrome and their families of all ages. We are particularly excited to be able to share some of our new projects and latest development work with you.

The Health Book for adults with Down's syndrome was launched earlier this year by Health Minister Jeremy Hunt at the House of Commons and it is now starting to be used by people with Down's syndrome and their families all over the country. The feedback from GP's has been brilliant because using the Health Book makes life easier for them. A doctor can find out important and very relevant information about a patient that has been put together by the people that know him or her best. Simple, but extremely effective! Members of staff from the DSA went to the World Down Syndrome Day conference in New York earlier this year to present the Health Book as part of the Health and Wellbeing theme and since then there has been considerable interest from other countries looking to use the format with their own adaptations.

WorkFit is really beginning to take off and we have been lucky enough to be able to employ two more WorkFit Officers, one in Wales and one in the North West. This means that we will be able to place more people with Down's syndrome into work and provide the support and advice to employers so that we can keep them in their job. I still find it incredible that since the outset of WorkFit, everybody that we have managed to place into work is still there. We haven't lost one. What a fantastic achievement!

POSEIDON is another really exciting project for the DSA working on a collaborative piece of work with other DS organisations in Europe and an international company that develops interactive technology to assist people with disabilities. We have done a huge amount of research and consultation with our members and the DSA is the lead organisation on this project. We hope to be able to tell you more about POSEIDON very soon.

There are some really important articles on SEN legislation, mental capacity, benefits and the Local Government Ombudsman. More on health issues for people with Down's syndrome and of course the lovely articles from our members. Please do take the time to read everything because although the information might not be immediately relevant to you and your family, it may be of use to others that you know.

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.

New DSA Staff

Alison Morgan Fundraising Manager

Alison Morgan joined the DSA in January 2014 as the new Fundraising Manager.

Alison started her career working in public relations in organisations including Mencap and the Youth Justice Board. She then gained experience in fundraising whilst working at The Institute of Cancer Research for over ten years before she headed up the fundraising team at the Mayhew Animal Home.

Alison is delighted to be now working at the Down's Syndrome Association.

I am very lucky to be joining a lovely team. Before I started, I assumed the DSA was a large charity but that's not the case and I'm so impressed that so few people achieve so much.

Fundraising is never easy but I am very excited to take on this new challenge. I'm confident that working with such a dedicated team and importantly with our amazingly loyal supporters that we can continue to raise enough funds to help thousands of people with Down's Syndrome and their families across the UK.



Contents

DSA

Letter from the Chief Executive	2
Staff at the DSA	2
Awareness Week	4
My Perspective Photographic Competition	6
Morgan Lovell Transform the DSA Offices	7
Wales News	8
Information Exchange Days	9
All Change for SEN Legislation	10
Visual Resources for Social Inclusion	12

RESEARCH

Alzheimer's Disease in Down's Syndrome	13
Dual Diagnosis Forum	14
Poseidon Project	15

HEALTH

Health Update	16
Neck Instability	17

MEDIA

New Look for the Down 2 Earth Magazine	19
Shhhhh...it's all on Shmedia	20

BENEFITS

For those claiming ESA	22
------------------------	----

NEWS

The Mental Capacity Act	24
In Memoriam: Harry Whitaker	25

FEATURES

Prisca	26
Who really decoded Down's syndrome	28
The LGO and you	30

TRAINING

Training at the DSA	32
---------------------	----

WORK

WorkFit	33
---------	----

SPORT

DSActive	34
----------	----

IT

Using a Smartphone	35
--------------------	----

OUR MEMBERS

My Son Oliver Hellowell	37
Aim for the Moon... that way you're bound to reach the Stars!	39
Esmee	40

BOOK REVIEWS

Gross Motor Skills for Children with Down Syndrome	42
I Love You Natty	42
The Essential Guide to Health Care	43
KILLA	43

OBITUARY

Peggy Fray	43
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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: Photograph of Prisca by Mariana Melo Lima. See page 26.

Awareness Week

Better Health Care for Adults with Down's

“Thank you for the Health Book. It is an excellent idea. I always worried about what would happen if I was not around and my son had to go to the doctors – now I don't have to”

Comment from a parent member whose son had received the Health Book.



During Awareness Week 2014 we campaigned for Better Health Care for Adults with Down's Syndrome.

- We wanted to give adults with Down's syndrome a sense of ownership over, and involvement in, their own healthcare
- To facilitate improved long term record keeping that would benefit people with Down's syndrome, medical practitioners and others who provide support
- Provide GP's with tools to guide them through the necessary health checks and to signpost them to further information about specific Down's syndrome related health conditions

In order to achieve these aims we developed the new DSA Health Book to support adults with Down's syndrome and their families to obtain a thorough Annual Health Check and assist at regular visits to the surgery.

The Health Book gives GPs all the medical history they need in one place and is supported by a specialist website, www.dshealth.org.uk. Created for GPs and health professionals it provides detailed information on the common medical issues that can affect people with Down's syndrome.

During Awareness Week we encouraged our membership and supporters to contact their local GP and give them information about the Health Book and our website. Our Awareness Week pack included materials which could be downloaded from our website.

Another important aspect of the campaign was to reach adults with Down's syndrome who are not members of the association. We spread the message far and wide that membership is free for adults with Down's syndrome.

The campaign also involved the younger generations, as it is never too early to start promoting and talking about good health. We prepared easy read healthy eating and keeping fit factsheets which were widely used by families and schools to have fun raising awareness.

17 - 23 March 2014

Syndrome

To ensure that as wide an audience as possible heard and understood the importance of the Health Book and GP website it was launched at a parliamentary reception hosted by Dr Hywel Francis MP and Chair of the All Parliamentary Party Group for Down's syndrome.

The reception was well attended and guests included the Health Minister Jeremy Hunt. DSA member, Sara Pickard delivered a flawless speech explaining why the Health Book was so important to her and other adults with Down's syndrome. Following this, Sara, along with Sheila Heslam, DSA Services Director, travelled to the United Nations, New York and presented to the World Down Syndrome Congress about the DSA's new Health Book and supporting GP website.



Dates for your calendar

Awareness Week 2015:

16 – 22 March 2015

World Down Syndrome Day:

Saturday 21 March 2015

Figures from Awareness Week 2014

- 364 Support Agencies and Local Authority Disability Teams emails despatched, 326 opened with 231 clicked through to our website
- Facebook total reach for the week 12,407,364 with 1,602,867 people engaged and 14,098 new likes
- 15,500 Twitter followers
- Website traffic – 53,446 unique visitors during Awareness Week.

The campaign is not finished – in fact Awareness Week was just the beginning.

- We want to encourage everyone who receives a Health Book to take it to every appointment
- We want to encourage adults with Down's syndrome to take up their FREE membership
- Encourage GP's to use their specialist website – www.dshealth.org.uk
- Ensure Care Providers know about the Health Book for people with Down's syndrome and use it
- Through the All Party Parliamentary Group for Down's syndrome ensure we gain Department of Health approval for the Health Book.



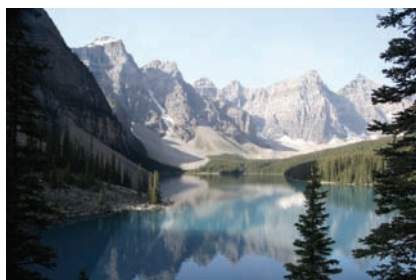
During Awareness Week the DSA ensured that we showed our support for World Down Syndrome Day by wearing Lots of Socks

My Perspective Photographic Competition 2014



The Winners

The very talented Stephen Thomas aged 17, was announced as the Overall Winner of this year My Perspective Photographic Competition for his picture "Moraine Lake".



Stephen Thomas, Moraine Lake

Stephen has been taking pictures since he was 8 and uses a Canon 1000D to capture his stunning images. When asked why he likes taking photographs Stephen said

"I like taking close-up and seeing all the details in things. I like taking landscapes. I would like to do more photography especially landscapes and flower close-ups. I would like to take photos as my job."

Upon being announced as this year's winner he said

"I'm so happy."

Now in its fifth year, the annual competition is open to anyone with Down's syndrome and the only rules are that you must have Down's syndrome and you must have taken the photograph yourself.

The Down's Syndrome Association launched the My Perspective competition to allow people with Down's syndrome the chance to show us their perspective of the world around them. The competition has grown from strength to strength and receives entries from around the world. This year saw entries from Greece, Indonesia, USA and even as far as New Zealand.

The awards ceremony was held in the beautiful surroundings of Kew Gardens and attended by over 200 people.



Stephen & Georgie

Stephen's family including his Dad, David, Mum Julie and big brother Paul who cheered with delight as he went to receive his prizes from DSA Patron Georgie Hill, assisted by last year's winner Daniel Tones. Stephen received a Canon ES1100D camera and bag, along with a canvas print of the winning image and certificate, along with the honour of being a judge next year.

Joint second prize winners both attend the Cricket Green School in Mitcham which runs an excellent photography programme. The school had eight pupils enter, three of which were shortlisted.



Tim Beale, Chilling Out



Rosika Edmund, Flower Poem 2

Joint Second Place Award

Both runners up receive a camera, canvas print of their image and certificate.

Tim Beale - Chilling Out

Rosika Edmund - Flower Poem 2

Runners Up

All runners up received a canvas print of their image and certificate.

Carlos Biggemann - Spread Your Wings Little One (from New Zealand)

Graham Busby - A Bug's Life

Beth Courtma - Under the Tree

Christopher Diedo - Houses of Parliament and Creepy Tree

Sita Dommett - Planting Rice in Bali

Fratzeska Douka - Blue Sky (from Greece)

Katy Francis - My Dancing Feet

Daniel Geeson - Tulips (from Powys)

Maria Georgiadou - The Old Lady (from Greece)

Edward Giffin - Sunset Through the Window

Daniel Harrison - Abstract 2 from Cricket Green School

Rachel Ireland - My Shadow (our youngest entry aged 7)

Darren Jones - Sunset

David Kenward - Poppy Field

Maria Mantzopolopoulou - The Sea (from Greece)

Edward Phippen - Beach on Tiree

Shane Roussi - Star Spangled Banner (from Ohio)

Gabrielle Shann - Escape

Karen Slater - On the Table

Ermis Vouvounis - The Flowers (from Greece)

Zoe Wilton - The Bees and the Butterflies

2015 – Get Ready to Enter

Entries for next year's My Perspectives Photographic Competition can be submitted from October 2014 until early April 2015. The entry form is on our website.

We encourage everyone to take some pictures with a camera. You can also use a phone or tablet. We look forward to receiving your three images for judging.

GlaxoSmithKline have generously sponsored My Perspectives Photographic Award since its conception in 2010. Their continuing support and commitment to the DSA allows this unique project to grow year on year.

Morgan Lovell Transform the DSA Offices

In December 2013 Morgan Lovell and their annual Charity SOS project transformed the offices of the Down's Syndrome Association in Teddington.



Third Sector Business Charity Award

Morgan Lovell believe in giving something back to charities across the UK. The project challenged them to completely redesign and fit out a charitable organisation's office for free.

Morgan Lovell commented before the refit took place:

After visiting their national office in Teddington, we saw that the amazing staff at the Down's Syndrome Association work in a challenging office environment. The present layout means that some areas are cluttered and overcrowded, making storage and organisation tricky. Team communication is hindered by the absence of collaborative areas and this is something we are keen to improve. The extreme generosity of the Down's Syndrome Association means that any spare cash goes straight back into helping those in need. This means that changing their office is not high on their priorities and is where Morgan Lovell can help. We know that even the smallest changes can make a big difference. So, every detailed decision throughout this project will aim to provide the DSA with a new level of efficiency, productivity and wellbeing.



Old furniture, fixtures and fittings were taken away for recycling. The refit included new desks, chairs, lighting and carpets.



The walls have murals and there is improved IT throughout the building. For the first time we have ample storage. A kitchen was installed in a new staff area. Meeting and assessment rooms were improved. The whole project was an amazing experience for all concerned.

On Tuesday 13 May ML and the DSA won a Third Sector Business Charity Award for the Charity SOS project at a ceremony held at the Grosvenor House Hotel on London's Park Lane.

Charity SOS was nominated under the Challenge Event category of the awards and we were in competition with M&S, Lloyds Bank/Alzheimer's Society, Investec/The Lord Taverners and ASK Italian/Great Ormond Street Hospital.

Charity SOS was a truly uplifting and rewarding project to have been a part of; not just because it gave the DSA incredible new offices, but because of the people we worked with. Everyone, from the senior consultants down to the interns and painters and decorators, put their heart and soul into this project for the DSA and we could not be more grateful. To be able to top off the whole experience with an award win was just the icing on the cake!

With thanks to the staff at Morgan Lovell from all at the Down's Syndrome Association for giving us such wonderful new offices!



Simon James

Simon James joined the Association in June and will be responsible for rolling out the WorkFit programme across Wales. Simon will be making links with prospective employers, providing them with training sessions focused on supporting adults with Down's syndrome in the workplace and acting as a link between employers, individuals with Down's syndrome and their families and other agencies such as Job Centre Plus and local supported

Wales News

By Julian Hallett, DSA Wales Manager

2014 is proving to be an exciting year for the Association is Wales! Following our success in being awarded 3 year Big Lottery funding at the beginning of the year, we have now appointed our new WorkFit Wales Employment Development Officer.

employment agencies. Simon has extensive experience in supporting people with a learning disability into employment, having worked as a Development Officer on a Work Choice Programme in West Wales and also as an Employment Advisor for a leading supported employment provider.

For more information or to contact Simon, email wales@downs-syndrome.org.uk.

Speaking of his new role, Simon said:

"I'm very happy to be joining the team and building on the success of the WorkFit model and starting our new project in Wales. I'm looking forward to meeting families of young adults with Down's syndrome who are considering employment options and hope that we can work together in helping these individuals to achieve their potential".

We are delighted to report that we are already working with a number of new employers in Wales who have signed up to the WorkFit model – one recent organisation to sign-up is Cardiff University.

Julian Hallett, Wales Manager, has had a busy period delivering training for a wide variety of audiences across Wales and is pleased to note that The DSA has recently been commissioned by a number of organisations including Learning Disability Wales and several Welsh local authorities to deliver sessions as part of their published training programme. These have included new sessions on health and ageing. These courses, together with lots of training work in schools, Early Years settings and training for Universities running courses for student medics and midwives, means that we are reaching an ever more diverse population of professionals involved in supporting people with Down's syndrome across the life-span.

North Wales Development Officer, Jane McIlveen, has been focused on arranging a residential weekend conference for new families of children with Down's syndrome. Thanks to funding from Families First Conwy, we were able to facilitate a very successful event in Pengwern Hall, Denbighshire, in August. Jane's work in recruiting volunteers and setting up local support networks continues. Jane can be contacted by emailing jane.mcilveen@downs-syndrome.org.uk



One of our Work Fit employees Sammy-Jo Hacker from South Wales, at a recent Understanding Disability Awards.

After a long and happy time at our Whitchurch Road Office in Cardiff – the decision was made that these (small!) premises had served us well, but as most staff spent their time out on the road, resources were better invested

in direct services. From now on our Wales Team will be mobile across Wales and contactable via our National Office helpline on **0333 12 12 300**.

Email addresses remain the same.

Information Exchange Days 2012-2014

There are approximately 120 local parent-led groups affiliated to the DSA that provide support to people with the condition, their families and carers. Each group has its own identity and functions independently, some are registered charities in their own right with an active events schedule and other groups meet in an ad hoc manner, providing an opportunity for parents to swap stories and lend a listening ear.

In 2012 here at the DSA we embarked upon a programme of regional Information Exchange Days. We felt that regional events were more likely to attract people than a one off single location event. We also felt that the additional benefit of smaller regional meetings was the added value of being able to address local needs, look for national patterns and develop stronger relationships.

We wanted to meet representatives from as many groups as possible, let them know what we were up to, find out about their activities and look at ways in which we could work together and support each other in the future.

Each day was loosely based around a similar format with time being given to individual segments according to the interests and issues of those present.

- Information and updates about DSA activities
- Exhibition of new DSA resources
- Information and updates about support group issues and activities.

The DSA has been developing a number of new resources over the past two years including the Adult Health Book and social care assessment factsheets, the feedback we were given at the Information Days helped us to get them right. The last section of each day was really important to us as it focussed on the future and what needed to be done to support people with Down's syndrome and their families, a big task! Many issues were brought up by local groups including; transition to adulthood, social care services, group governance, and speech and language support. We have already begun to address some of the concerns raised at the Information Exchange

Days and have plans to do more when funding becomes available.

Most groups told us there was poor support and planning for young people with Down's syndrome moving towards adulthood and that they have to proactively push for the involvement of services in their child's transition planning and for information about what options are available. A universal concern is about inadequate and poor quality FE courses and the lack of a clear path of progression for people with Down's syndrome after college. There seems to be highly variable support for adults with Down's syndrome even within the same locality.

We have been given funding to enable us to offer three separate workshops which provide families with information about planning for the future, supported decision making, the Mental Capacity Act, supported living, employment, changes to education and social care law. The workshops are a general introduction to the things families need to consider, the people who should be involved, and what their role is. We hope to offer this to more regions subject to funding. New resources about supported living, the Mental Capacity Act, assessments and education changes have been produced alongside the workshop. These are available to download free from our website.

There seems to be a general lack of awareness amongst groups and families about the social care system and who to turn to for help. For example, awareness of the rights of carers to a carer's assessment was generally low. Groups report misinformation from social services whereby parents are told, that their child is not eligible for support without an assessment having taking place. Poor and inaccurate social care assessments appear to be a common issue for families as well as uncertainty about personal budgets and what they may be used for. We have developed a series of practical factsheets to help families understand the process and ensure they get the best out of it. Available for download from our website are:

- Asking for a Community Care Assessment

- Preparing for a Community Care Assessment
- Getting the Care Plan Right
- The Carers' Assessment
- Preparing for a Social Care Assessment for Your Child.

We would love as an organisation to be able to deliver more training and workshops but we are constrained by the small size of our team and funding. In order to get around these issues we are considering developing alternative methods of delivery like video clips and on-line training to give people the information they want and need. Our Benefits Officer has already paved the way by giving a presentation via Skype to the Swindon group and in June Gill Bird collaborated on a joint Facebook question and answer session based around communication strategies with the National Children's Deaf Society.

The development of resources to support children in schools was another thing asked for by parents and Gill's article in this Journal 'Tools for Inclusion' will tell you what we plan to do in this area. We also have funding bids out for:

- An assessment, school support and training service
- The development of practical resources and information to support social inclusion at home, in schools, work places and in the wider community
- An exciting project to develop resources and a forum for people with Down's syndrome.

We are very grateful for the positive reception we received from the Support groups who have been really keen to share experiences and ideas with each other and the DSA. The majority of groups tell us that as a result of coming along to an Information Exchange Day they had learnt something about the DSA's work they did not know before. The overwhelming message from groups is that ongoing and regular face-to-face contact with the DSA is absolutely necessary for the successful sharing of ideas and information. We hope to be starting a new round of days later this year; information about this will be posted on social media and the Local Groups page of our website.

All Change for SEN Legislation

Lesley Black, DSA Information Officer (Education)

Note – the change in legislation applies to families living in England only. The system in Wales and Northern Ireland remains the same; the Welsh government is likely to introduce a Bill with wide ranging reforms during 2015.

This September has seen the coming into force of the Children and Families Act 2014. Part 3 of the Act, relating to special educational needs, has been billed as the biggest change to the SEN system in 30 years. The Act is also accompanied by a new Code of Practice.

Parents are naturally concerned about how the new system will affect their children's education and confused about how things will work in practice. What will change, when and how?

This article will attempt to pick out some of the main changes and answer some of the questions.

Background

In recent years a number of reports have identified widespread dissatisfaction with assessment of and provision for special educational needs. In 2011 the government published the Green Paper 'Support and Aspiration: a new approach to special educational needs and disability'. This seemed to promise a completely joined up system between education, health and social care with a single assessment process. Whether the new system measures up to this ideal is open to debate.

The legislative process has been long and complex. The DSA has been involved in trying to safeguard the interests of children with Down's syndrome, both through our own submissions and through our membership of the Special Educational Consortium.

In parallel with the legislation going through parliament, the reforms have been trialled in a number of 'Pathfinder' local authorities. Evaluation reports appear to be positive but it must be borne in mind that the pathfinders had increased resources and the number of families involved was fairly small.

The situation has also been confused by the fact that changes to the school funding system for SEN came into force a year ago, making schools responsible for paying the first £6,000 of additional support from their own budget.

Overview

Some of the main changes included in the Children and Families Act include:

- A single system covering ages 0 - 25. This aims to avoid a gap in support when young people leave school. Young people will have the right to ask for a particular college to be named and the right to go to Tribunal over educational provision in further education
- Statements will go and be replaced by Education, Health and Care Plans (EHCPs). These will be triggered by educational need but may also include health and social care provision
- A single category of SEN support for children without EHCPs – School action and school action plus will go and there will be no requirement for IEPs
- Parents and young people will be given the option of a personal budget

for special educational provision. In some cases direct payments may be available.

Although part 3 of the Act came into force on 1 September, not everything will change at once. Complete phasing out of statements is likely to take several years.

How it will affect different groups

Parents, children and young people

The new system aims to put parents and young people at the heart of decision making so that they are working with schools and local authorities rather than having things done to them. There is a new emphasis on person centred planning.

Parents, children and young people must be involved in planning e.g. developing the local offer.

Young people over 16 will have new rights to make their own decisions regarding education. This includes applying for statutory assessment and appealing to tribunal. There will be provisions for those young people who do not have the capacity to do this.

Schools

Schools will be given more freedom as to how they organise the support for children without EHCPs. The code of practice recommends regular cycles of 'assess – plan – do – review', but it will be up to the individual school how this is done. There are no longer clear triggers as to when a statutory assessment might be necessary.

The focus is on providing high quality teaching for all.

Colleges

Colleges are brought within the SEN framework for the first time. They must use their best endeavours to provide the necessary support for young people with SEN. Young people with an EHCP attending college will have a legal right to the education provision set out in the plan.

Local authorities

Local authorities' responsibilities have been widened in a number of areas. As well as information, advice and support to parents, LAs must now provide this separately to young people in their own right.

Each LA must publish a 'local offer' detailing what provision and support is expected to be available for children and young people with SEN or disabilities including:

- What support local schools can provide for children with SEN
- Information about assessments and plans
- Leisure
- Childcare
- Support for moving to adulthood
- Transport.

Local authorities have responsibilities for joint working; they must ensure integration between education, health and care provision. There is also a new duty to have joint commissioning arrangements for education health and care provision in response to local need.

What will it mean for you – some questions answered

Will my child lose her statement on 1st September?

Definitely not. There will be a transitional period while the new system is rolled out; children and young people will be moved onto the new system over several years, starting with those new to the system or moving to another phase of education. In the interim, local authorities must continue to maintain and review existing statements. The only circumstance is which the LA could cease a statement is if your child no longer requires special educational provision.

The definition of SEN in the new law has not changed so anyone who was eligible for a statement should be eligible for an Education, Health and Care Plan. In an open letter to parents, Edward Timpson, Minister for Children and Families, has assured parents that no child should lose support because of the changes.

My son is due to leave school next summer and go to college. What happens about his statement?

Under the old system his statement would have ceased and the local authority would have to carry out a section 139a learning difficulty assessment (LDA).

There will be no new LDAs or statements from September 2014. Your son should be moved onto an Education Health and Care Plan during his last year in school, probably following an annual review. You should raise this with the LA and school early in the year and ensure that you start gathering any health or social care evidence.

Will there be a single seamless assessment?

That was the hope. However the legislation does not require this. There is a recommendation in the code of practice to adopt a 'tell it once' approach; however that does not mean that there will be a single assessment with all professionals present. What the LA can do, is to use already existing evidence for the assessment instead of asking for new reports from professionals. You should be sure that you are happy before agreeing to this. For instance, if your child's needs have changed, ask for a new report.

Will my child now have an automatic right to social care support?

No. It is true that social care has been brought within the remit of Education Health and Care plans. However, the assessments and plans remain education driven and will not automatically trigger a social care assessment. If your child is not already known to social care services, it is not likely that they will provide a report for an EHC needs assessment. You should contact your local children's disability team separately to ask for an assessment. This can then be incorporated into the EHCP.

You should be aware that some services such as short breaks may be available without an assessment, so your child may not be flagged up as needing social care provision.

Can my son now stay in education until he's 25?

Not automatically. EHCPs can continue until age 25; however that does not mean that they must. There is a duty for young people to remain in education until age 18. For young people over 18 the LA must maintain the plan if it is necessary for them to do so. They would need to look at whether the outcomes of the plan have been met and whether the young person still requires special educational provision. They are also likely to consider whether the young person would progress rather than repeating what they have already done. If the LA decides to cease the plan, the young person has a right of appeal to Tribunal.

What status will speech and language therapy have in the new plans?

Following intervention by SEN organisations and others, the government has upheld existing rights in this area. Speech and language therapy (and other health care provision) that educates or trains a child is to be treated as special educational provision which the LA has a duty to arrange. If your child has an EHCP, make sure that SALT is in the education section, not the health section and that it is specific and quantified.

Can I appeal to Tribunal over the whole plan if I'm not happy?

No. The situation will remain much as it is and there will not be a single point of appeal across education, health and social care. You will be able to appeal about the education part of the plan and the name of the school or other institution named. You will not be able to appeal about health or social care provision. There will be separate mediation and complaints procedures for this.

If you want to appeal about the education content of a plan you will now be required at least to consider mediation and get a certificate from a mediation adviser before you can lodge an appeal with the SEND tribunal.

More information

Please see the DSA website for more information on your rights in SEN.

Visual Resources for Social Inclusion

Gillian Bird

Visual Resources

We often speak about how visual resources and visual teaching methods can help people with Down's syndrome at all stages in their lives. We use visual resources to help children learn at home and at school, often by enabling them to access an age appropriate curriculum with their peers, and to support adults in all aspects of their lives.

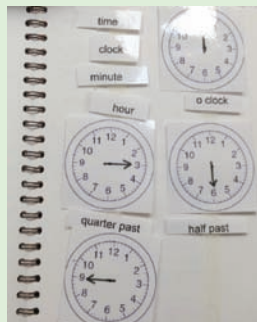
Through interactive resources, children and adults can participate, express themselves and communicate with others. As parents and practitioners, we show and model how to do things, for example, for teaching new play skills, signs, for reading, drawing, counting, for showing positive behaviour, for physical activities and for every type of practical skill. We use visual teaching resources to directly teach social skills, language, literacy and numeracy. We make personal books and eye catching resources to motivate and engage people in their learning. Visual methods help us to explain ideas, support language comprehension and communication.

Visual schedules, timetables, memory aids and work guides help children and adults understand, remember and complete tasks. These resources can promote confidence, competences and friendships, particularly in the classroom, where simple guides can enable children to work with their peers with less direct help from an assistant.

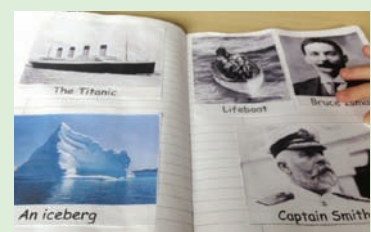
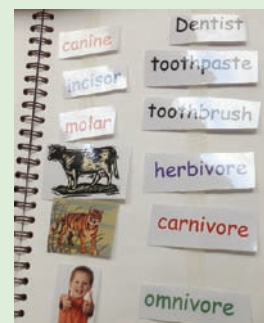
DSA Resources

We are in the process of creating resources that will be free to members through our website. We will explain the reasons for providing the examples, activities and resources so you know why, when and how they were used. We will be asking for your ideas and to give us feedback. We have started to collect examples of school resources which build on our Primary and Secondary Education Support Packs and Celebrating Success series. <http://www.downs-syndrome.org.uk/information/resources-for-students.html>

For example, we will help schools to create a **bank of resources** that can be prepared in advance, for use in any lesson (e.g. shapes, coins, days of the week, months of the year shown below):



We will also show examples of topic and activity specific resources and explain how to use them. For example, the resources shown below have been created to support engagement during parts of specific lessons or activities. They do not show the end product or record the child's work, but are the tools used to help the children learn. Some resources have been prepared in advance of lessons and some were prepared during lessons. Students have enjoyed helping to create them.



New resources for people of all ages

As well as providing examples, such as those illustrated above, we will create new resources to aid social inclusion for people of all ages although we need funds to progress these parts of the project.

The resources will be easy to understand and use. They will encourage people to use the full range of visual resources to help people succeed.

Alzheimer's Disease in Down's Syndrome

From Molecules to Cognition

By Stuart Mills, Information Officer

Parents and carers sometimes get in touch with the DSA because they are worried about Alzheimer's disease in their relative or the person they support.

Alzheimer's disease is the most common form of dementia seen in people with Down's syndrome. Whilst all people with Down's syndrome are at risk, many adults with Down's syndrome will not manifest the changes of Alzheimer's disease in their lifetime.

Although risk increases with each decade of life, at no point does it come close to reaching 100%. So Alzheimer's disease is not inevitable in people with Down's syndrome.

The difference for people with Down's syndrome is that, if it happens, Alzheimer's disease occurs at an earlier age than is usually seen in the general population.

Many of the common conditions related to ageing can be mistaken as Alzheimer's disease if not identified properly (e.g. hearing loss, low thyroid function, vision loss, pain, B12 deficiency, sleep apnoea, depression). Since these are treatable, it is really important to have a full medical assessment at an early stage in order to rule them out. If you have any concerns about Alzheimer's disease and someone with Down's syndrome, it is important to raise these with the person's GP.

The DSA recently attended part of a three day conference at the Wellcome Trust, Cambridge about Alzheimer's disease and people with Down's syndrome. The overall aim of the conference was to provide a better understanding of dementia in Down's syndrome at the neurological, cognitive, behavioural, cellular and genetic levels.

It was really positive to see an auditorium packed with clinicians and academics from across the world with an interest in this field of research.

One of the factors, in what is a complex picture, behind the development of dementia in people with Down's syndrome is the extra copy of Amyloid Precursor Protein (APP) gene that they have.

Professor William Mobley (University of San Diego) spoke to conference about the importance of exploring the mechanisms that causes Alzheimer's disease along with the need for testing disease modifying treatments in populations that are genetically predisposed to Alzheimer's disease. Professor Mobley and his team are looking for ways to stop the over secretion of APP and therefore remove one of the factors that leads to dementia in people with Down's syndrome.

A number of other studies were presented looking at various biomarkers (other than APP) that may contribute to people with Down's syndrome developing dementia and identifying biomarkers that may lead us to be able to spot dementia in someone with Down's syndrome at an earlier stage. If successful, this would mean that we would have the ability to provide better care and treatment at an earlier stage in the condition.

Closer to home, the London Down Syndrome Consortium are doing some interesting work looking at cognitive, genetic and cellular profiles that influence how the brain works in people with Down's syndrome and their influence on the chance of developing Alzheimer's disease. Find out more about their work <http://www.ucl.ac.uk/london-down-syndrome-consortium>

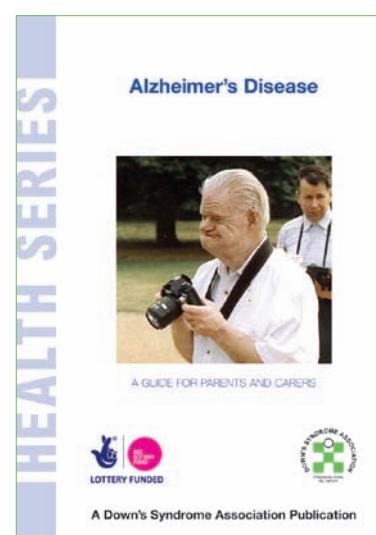
One of the driving forces behind research into dementia and people with Down's syndrome is the fact

that everyone with Down's syndrome eventually has the physical signs of dementia (plaques and tangles) in their brains but a proportion of people do not develop dementia. What is protecting this group of people? The answer to this question might have profound implications for the general population.

Needless to say, research in this field is in its very early stages and it may be many years before we begin to see any benefits for people with Down's syndrome.

We have developed a page on our website with some basic information about Alzheimer's disease. We would very much like feedback and your suggestions for additional information that you would like to see on the web page.

You can send your feedback and suggestions to stuart.mills@downs-syndrome.org.uk





It was obvious from some of the conversations taking place that a dose of humour coupled with inventiveness played a big part in helping parents to deal with some challenging situations.

After lunch DSA staff asked parents to share their experiences of supporting positive behaviour in their children. Some parents had brought along communication resources which had helped their children to make choices and to express their wishes.

People attending raised a number of subjects they would like to see at future meetings including preparing for adulthood, communication, meeting sensory needs and diet. Gill Bird will be addressing communication at our next meeting on 4 October 2014. In addition, Dr Parr, Clinical Senior Lecturer/Hon Consultant at the University of Newcastle and Dr Newall will be talking about their research looking at the range of ability and numbers of children with Down's syndrome who also have atypical behaviour and whether screening between the ages of three and five can indicate ASC in children with Down's syndrome.

Dr Parr also leads the Autism Spectrum Database-UK, which is a database of families of children with ASC, who have shown interest in participating in research.

If you would like to find out more about the Dual Diagnosis Forum, future meetings or the condition itself please look at our website or contact info@downs-syndrome.org.uk and one of our information officers will get back to you.

Speaker confirmed for 2015:

Saturday 18 April 2015 – Paul Isaacs (Autism Oxford) talking about living with autism.

Please email stuart.mills@downs-syndrome.org.uk if you would like to attend.

Dual Diagnosis Forum

By Vanda Ridley, Communications Manager, Down's Syndrome Association

The DSA holds a meeting twice a year for parents of children who have dual diagnosis of Autism Spectrum Condition/Down's syndrome (ASC/DS) or who feel they would like to know more about this area.

Each meeting has an expert guest speaker providing information in the management and understanding of the condition. The meetings are an opportunity for people to get together, share their experiences and make new contacts.

Many of the parents who attend also belong to an on-line forum which helps provide the direction of future meetings. The forum is a place where parents and carers of children with ASC/DS can talk about any issues that concern them and get advice from each other. Details of how to join can be found on the Dual Diagnosis page of the DSA website.

In October 2013 Gill Bird, the DSA's developmental psychologist, gave a presentation which explored current thinking in regard to behaviour management and offered some practical solutions. Some of the issues raised were; how to support positive behaviour, developing communication skills, offering choices, play and leisure skills, setting expectations and rules, social stories and teaching and learning activities at school. Gill's presentation can be found on the 'Dual Diagnosis' page of our website.

In April this year we were lucky enough to welcome Professor Jeremy Turk to the DSA National Office to talk to parents about the use of medication in supporting behaviour. Professor Turk is a Consultant Child and Adolescent Psychiatrist at the London and South Maudsley NHS Trust and a Professor of Developmental Psychiatry at the Institute of Psychiatry. He is passionate about the mental health needs and welfare of children and young people with learning disabilities, and also those of their families.

Professor Turk spoke about when medication might be useful and emphasised that it should never be the first step in tackling a behaviour issue. Medication should only be considered once positive behaviour intervention strategies have been tried. He went on to say that once a decision has been taken to use medication this must not be in isolation. Everyone involved must continue to work together in supporting the young person's behaviour (family, school, social care, carers, health).

Professor Turk also sought to dispel some of the concerns held around medication by highlighting the targeted and refined nature of current medications now available, compared to the 'blunt instruments' such as Valium which were widely used in the past.

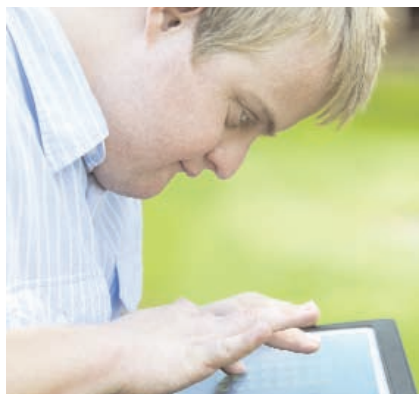
One of the major benefits of the ASC/DS meetings is for parents to meet together and share their experiences. There were many lively discussions throughout lunch and the chance to share information at our refectory table in our wonderful, newly refurbished, basement area (thanks to the support of Morgan Lovell).



POSEIDON

PersOnalized Smart Environments to increase Inclusion of people with DOWn's syNdrome

Vanda Ridley, DSA Communications Manager



In case you have not heard about it yet POSEIDON is an exciting, three year project which has been funded by the European Commission.

The goal of the project is to create information technology which will help people with Down's syndrome to achieve a greater level of independence in their lives. The technology will support people to develop and socialise at home, in education, at work and at leisure. Types of technology that may be developed will include apps for tablets and smartphones, virtual reality programs and interactive visual tables.

The project team includes members from the DSA, Middlesex University, and the National Down's syndrome associations of Germany and Norway and from a number of technology research and development companies based in Germany, Sweden and Norway.

The Project was launched in Oslo last November and The POSEIDON Partners would like to thank everyone who took part in the on-line survey about their use of IT.

All the data collected from The UK, Germany and Norway has been invaluable to the technical developers in the early stages of this project. We are also grateful to the thirty individuals who agreed to be interviewed about their daily lives. The interview provided a detailed snapshot of both the joys and challenges each person experiences.

As the project is funded by the European Commission it has been important to get the views of people outside of the three countries the partners come from.

Therefore in January we all met in Oslo where four people with Down's syndrome were invited to talk about their lives and the technology they used. The individuals came from Slovenia, Croatia, Italy and Rumania and were accompanied by a family member and a representative from their national Down's syndrome association.

Each person gave a presentation about themselves and was asked to try a number of different apps. They were filmed 'in action' so the technicians could see how difficult or easy they found each app to use. It was very interesting to find out about what life was like for people from other parts of Europe.

Serena (39) travelled from Italy and is a keen sportswoman and a Global Olympic Messenger for her country. Her dream is to become a secretary and she lives at home with her mother.

Gregor (22) from Slovenia lives at home with his parents. He loves computer games and using his exercise bike. His father is worried about what opportunities there are for his son and is campaigning for better supported living in Slovenia. Currently many young people move into flats in a complex with carers if they leave home. Gregor's father is concerned about the quality of care and activities available.

Vicki (15) from Croatia lives with her parents. Once Vicki is 16 she will have the opportunity to train as an assistant florist.

Laurentiu (15) from Romania just loves his family and school (as long as he does not have to work too hard) and has many friends.

There will be two further workshops in Mainz, Germany and London. By the

time you read this article the workshop in Mainz will have taken place. As I write we are preparing for the workshop and hope to have some prototypes which our guests can try.

We have invited representatives from Portugal, Switzerland, Luxembourg and The Ukraine. The first prototypes will focus on navigation apps to support people when they are out and about in their own communities. There will also be a virtual environment app to help with travel training.

The first pilots will be run next January and we will be looking for families in the UK who are willing to trial the prototypes for a month with support from us at the DSA and Middlesex University.

Juan Augusto who leads the project at Middlesex University, would also like to organise some additional days, the first being towards the end of this year, where groups of young people can gather, try out what has been developed so far and give their views. This will make sure that the developers are on the right track and produce something useful. Keep checking the POSEIDON page on the DSA website as we will be asking for people to volunteer to be part of these groups.

The February Journal will have information about the Mainz workshops and an article by Juan Augusto who will be talking in detail about his team and the work they are involved in at Middlesex University on behalf of the project.

I will also keep you up-to-date with developments through the DSA blog, social media and via the POSIDON page on the DSA website. The next few months are going to be very exciting as the technology comes off the drawing board and into the testing stage.

POSEiDON
www.poseidon-project.org

Health Update

As an organization, the DSA has had a consistent focus on improving the health and healthcare of people with Down's syndrome. By engaging people with Down's syndrome their families and carers, medical professionals and parliament, the DSA aims to prioritise better health for all people with Down's syndrome.

This update aims to keep our members and supporters informed about the main areas the DSA has recently been working on concerning health.

Health Book

As many of you may be aware, the DSA has produced an 'easy read' Health Book for adults with Down's syndrome. This was created as a response to a DSA survey of adult Annual Health Checks, which found that too many people were experiencing less than satisfactory checks, and that some were not even receiving an Annual Health Check. The Health Book is divided into two with a part for the owner to fill out (with help if necessary) including their personal details, existing health issues, how they communicate and their ability to undertake various daily living skills. There is also a section for the GP to complete with details of the tests and health checks that have taken place. This section guides the GP through the areas of health needing to be considered as a part of an annual health check for an adult with Down's syndrome. Whilst the GP is working through their section of the Health Book they can refer to our website for GPs at www.dshealth.org. This contains information about more common health conditions found in Down's syndrome.

During Awareness Week 2014, the Health Book was sent to all our adult members with Down's syndrome. We hope that the Health Book will improve the experience of people with Down's syndrome having annual health checks, as well as their general routine appointments with their GP and other health professionals. We believe that this simple tool can give adults a sense of ownership over their own health care, and may improve long term record keeping about the health and daily living skills of individuals.

Whilst we cannot say for certain that there is a connection, we have seen a significant number of adults joining the DSA for the first time since the Health Book was launched. Here is some of the

feedback we have received from families:

Thank you for the Health Book. It is an excellent idea. I always worried about what would happen if I was not around and my son had to go to the Doctors – now I don't have to

We feel this book is easy to understand and to see the vital information at a glance. We are both in our seventies and a book like this is great for an emergency. Thank you very much for this brilliant idea.

My daughter just received her Health Book. What a great idea. Thank you

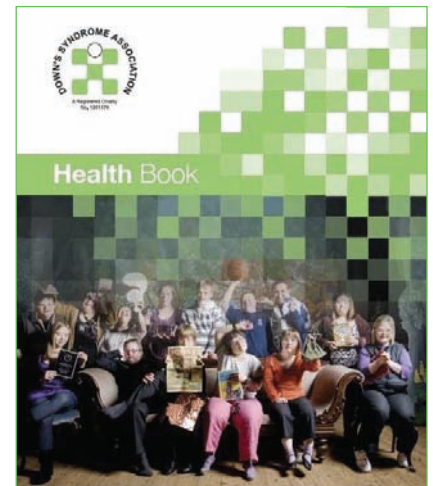
We very much want to hear what you think about the Health Book, and we will be carrying out a formal evaluation using an electronic feedback form this autumn. Keep an eye on the news section of our website for details of the evaluation. If you have received a Health Book and want to tell us what you think now, please email: stuart.mills@downs-syndrome.org.uk with your feedback. Alternatively, if you do not have access to the internet, you can send your feedback to Stuart Mills (Information Officer) at DSA's National Office.

We hope that have found the Health Book useful if you have received one. Please remember that you can download replacement pages for the Health Book at our website, and please tell your family GP about the website: www.dshealth.org.

We are currently working with the Down's syndrome APPG to secure Department of Health approval for the Health Book.

Leicester Care Pathway

In addition to our work on improving health care for adults with Down's syndrome, the DSA has also contributed to the Leicester Care Pathway. This is a guide for health professionals and families on the healthcare services



people with Down's syndrome can access from 0 – 21 in this area. It includes information on what the options are for children and young people and the health checks that need to be done to ensure good health. We have been talking to the author of the Leicester Care Pathway about ways in which we might encourage other trusts to tailor and adopt the Pathway. If you would like to read the Leicester Care Pathway, you can find it on the West Leicester CCG website:

www.westleicestershireccg.nhs.uk/sites/default/files/FinalDownsSyndromeCarePathwayforPrinting15032012.pdf

Medical Professionals

As well as providing publications for people with Down's syndrome and GPs, the DSA works with a number of different of medical professionals. We continue to partner with DSMIG (Down Syndrome Medical Interest Group). DSMIG was launched in 1996 and is a registered charity. It 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's syndrome. DSMIG members wrote a number of the titles in our Health Series, which was published in 2013. All titles in the Health Series are free to download from our website.

In addition to DSMIG, we have a small but growing number of health professionals with an interest in improving health for people with Down's syndrome who have joined our Adult Health Network. The DSA sends email updates to Network members about our health related activities, and we occasionally ask for their advice about health issues. The DSA is always looking for more health professionals to join our Adult Health Network. If you are a health practitioner with an interest in Down's syndrome and would like to join the

Network, please email stuart.mills@downs-syndrome.org.uk

Sharing Information – DSMIG and Hearing and Learning Disability Special Interest Group

The DSA also shares information with medical professionals. Stuart Mills (DSA Information Officer) gave a short presentation at the last DSMIG meeting (June 2014) about the development of the adult Health Book.

Stuart Mills gave a presentation in June about Down's syndrome and the work of the DSA to a meeting of the Hearing and Learning Disability Special Interest Group. Stuart focused on some of the areas of difficulty experienced by people with Down's syndrome and how these might impinge on their understanding of and co-operation during, a hearing test and how some of these difficulties might be alleviated.

APPG for Down's syndrome

Finally, the DSA has raised issues on health and Down's syndrome at a parliamentary level by continuing to work with the All Party Parliamentary Group (APPG) for Down's syndrome. An APPG is a group of MPs and Lords who meet together to discuss and promote a particular issue. The APPG also involves other groups and organisations who have an interest in that particular issue. The APPG on Down's syndrome aims to get the issues that affect people with Down's syndrome on the political agenda, influencing politicians to make real change. The current focus of the APPG is better health outcomes for children and young people. Dr Liz Marder (DSMIG) and Ian Maconochie (Royal College of Paediatrics and Child Health) recently gave a presentation to the APPG about a paediatric service specification for children and young people with Down's syndrome.

Further Information

If you have any questions about any of the projects included in this update, or if you have a more general health-related enquiry, please email the DSA at info@downs-syndrome.org.uk. You can also call our helpline for information at support. The helpline is open Monday – Friday, 10am – 4pm.

Neck Instability

Parents and those supporting people with Down syndrome to take part in sporting activities sometimes contact the DSA and DSMIG because they have heard that people with Down's syndrome can have problems with neck instability. This issue has caused some confusion and controversy over the years. Although it can potentially be a serious problem, this is rare and most people will have mild symptoms before dislocation occurs.

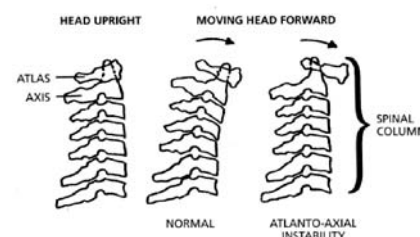
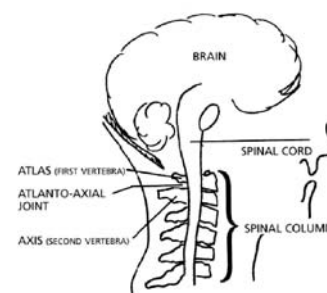
This article provides information to help parents and professionals to make informed judgments about risk and most important of all to recognize new, early warning signs that need further medical assessment. There must be a balance between encouraging people with Down syndrome to take part in and enjoy exercise whilst identifying those few individuals who may be at increased risk for dislocation so that timely investigation and if necessary, surgical intervention can be considered.

What is Neck instability ?

In people with Down syndrome the ligaments which stabilise the joints tend to be abnormally lax and this, combined with low muscle tone, results in an unusually wide range of movement at some joints. As well as affecting the ordinary limb joints, for instance hips and ankles, laxity can also affect the complex set of joints between the head and upper neck vertebrae. One of the functions of the vertebrae in the spine is to protect the spinal cord, a thick bundle of nerves, which runs inside the spine from the base of the brain to the pelvis. The main concern about neck instability is that this increases the risk of spinal cord damage, especially if vertebrae get misaligned

This is sometimes referred to as atlantoaxial instability or AAI to reflect the excessive movement which allows the top neck vertebra /first cervical vertebra or atlas, to slip forward over the second cervical vertebra, the axis,

which has a central peg that is well placed to damage the spinal cord (see Fig X)



Instability and movement can also occur between the skull and first cervical vertebra so the terms neck instability, craniovertebral instability (CVI) or cervical spine instability (CSI) are now more commonly used.

Can routine neck X-rays help predict risk in those with no symptoms?

Neck X-ray before taking part in vigorous activity has been recommended in the past (and still is in parts of the world

and by Special Olympics for some sports). This advice was changed in UK in 1995 when research concluded that neck X-rays did not reliably predict risk to the spinal cord. Neck X-rays from the same person with Down syndrome at different times can score differently, very few of the people with X-ray evidence of neck instability ever develop any symptoms of spinal cord damage, and a normal X-ray does not mean problems due to spinal cord damage could not develop.

What problems can be caused by neck instability?

Damage to the spinal cord in the neck can happen to anyone with or without Down syndrome, and can cause a range of problems from mild pain or a stiff neck to paralysis in extreme cases. This can either happen suddenly as a result of a sudden shift within the joint (for example whiplash causing dislocation), or more gradually because of day-to-day pressure on the spinal cord as the neck moves. Gradual onset of symptoms due to long term instability or degenerative arthritic changes is more common in adults with Down syndrome.

What to look out for

Fortunately most people have mild warning symptoms of problems in the upper spine before dislocation and long term damage occurs. It is therefore important that ALL carers and professionals working with people with Down syndrome are educated about warning signs of neck instability so that preventative action can be taken.

If someone you care for is showing any of these signs, they may have a problem with neck instability and should be seen urgently by a doctor:

- Pain anywhere along the neck.
- A stiff neck which doesn't get better quickly.
- Unusual head posture ("wry neck" or torticollis).
- Alteration in the way a person walks so they may appear unsteady.
- Deterioration in a person's ability to manipulate things with his/her hands.
- Incontinence developing in a person who has previously had no problems.

If the onset of symptoms is sudden an emergency appointment is needed. If there is no obvious alternative explanation for these symptoms they may be related to neck instability causing nerve damage, and an X-ray and specialist referral to either an expert orthopaedic surgeon or a spinal neuro-surgeon may need to be arranged.

What treatment is available?

If significant instability or dislocation is confirmed, and is thought to be causing problems, an operation can be done to stabilise the upper part of the spinal column and decompress any trapped nerves. The operation is delicate and is not without risk, particularly in younger children. Surgery should be performed at a specialist centre by an experienced specialist in this field. In experienced hands increasingly good outcomes are being reported. In the past there was a high rate of failure to achieve long lasting spinal fusion, however with contemporary techniques fusion is achieved in over 90% of cases.

Some children with neck instability require a period of traction to realign the joints and reduce pressure on the spinal cord before proceeding to surgical fusion. Keeping the bones immobilized after surgery whilst they heal can be difficult in children and so surgeons may use a "halo-body jacket" to provide external support for the neck for a few weeks after surgery.

Should people with Down syndrome be restricted from taking part in some sports?

The vast majority of people with Down syndrome do not have symptoms of neck instability and the question then is whether they should be excluded from certain activities which are associated with increased risk of neck injury?

It is clear that the very few neck injuries which have been recorded in people with Down syndrome whilst taking part in sporting activities were usually caused by tripping up or falling over, rather than by the sporting activity itself. In fact the injuries recorded would have been just as likely to occur in an ordinary person as a result of a similar fall or accident.

Increased exercise and fitness may increase muscle strength in the neck and be protective. On the other hand people with Down syndrome may be more at risk in some activities because they tend to be less well coordinated. These factors may well balance each other out. Therefore there should be no justification for special anxiety when people with Down syndrome are taking part in everyday routine sporting activities. There is no evidence that jumping on a mini-trampoline, early stages of horse riding or simple nursery forward rolls is any more risky for a child with Down syndrome than any of her peers.

However higher level sports such as trampolining, diving and boxing do carry an element of risk for anyone,

not just for people with Down syndrome, and for those with Down syndrome simple pre-sport screening is advisable.

The British Gymnastics Association has developed a simple screening protocol for those with Down syndrome who want to take part in trampolining and other higher level gymnastics. This involves ensuring the person has good head control, full neck movement (able to "look up to the ceiling and down to floor to tie their shoes") and has no evidence of spinal nerve damage or any of the above listed warning signs (download from www.british-gymnastics.org – Atlanto-Axial Information Pack). Very few have failed this screen and been excluded from sports at this level and it is encouraging to know that of the 400 or so people with Down's syndrome who have passed this screen no neck injuries have been sustained whilst taking part in gymnastics even at a very high level of performance.

What advice can be given about other activities which have increased risk of neck injury?

It is possible that because of a tendency to instability in the neck region people with Down syndrome may have an increased risk of whip-lash injury following road traffic accidents. We are not sure about this, but at the moment it seems sensible to recommend that properly positioned head-rests are always in place when a person with Down syndrome is travelling. Similarly, after a road traffic accident it is important to alert anyone involved at the scene to the fact that a person with Down syndrome may be more likely to have sustained a neck injury than another person.

Another point to be aware of is that doctors will need to take special care about positioning the neck during surgery requiring a general anaesthetic. There is virtually no risk of injury if the anaesthetist and recovery room staff are alerted beforehand to the fact that the person has Down syndrome.

Further references and information can be found in the Guidelines section at www.dsmig.org.uk – Information resources/Cervical Spine Disorders and in DSA Health Booklet on Neck instability available to download at www.downs-syndrome.org.uk

Pat Charleton, MB ChB, MRCPCH, MRCP. Pat is Chair of DSMIG (UK) and Associate Specialist Paediatrician and Clinical Lead for Down's Syndrome, Department of Community Child Health, Royal Aberdeen Children's Hospital.

A Brand New Look for the Down 2 Earth Magazine



Down 2 Earth Magazine is changing! Now in its 15th year of print, the DSA and editor of the magazine, Kate Powell, have decided to update the look and feel of Down 2 Earth for the September issue.

In case you aren't aware, Down 2 Earth is a magazine by people with Down's syndrome, for people with Down's syndrome. Launched in 1999, the magazine aims to provide a publication for people with Down's syndrome that is easy to read, fun and relevant to its audience. Each issue contains letters, stories, reports and photos from the editor and readers. All DSA members with Down's syndrome receive a copy of Down 2 Earth magazine twice a year.

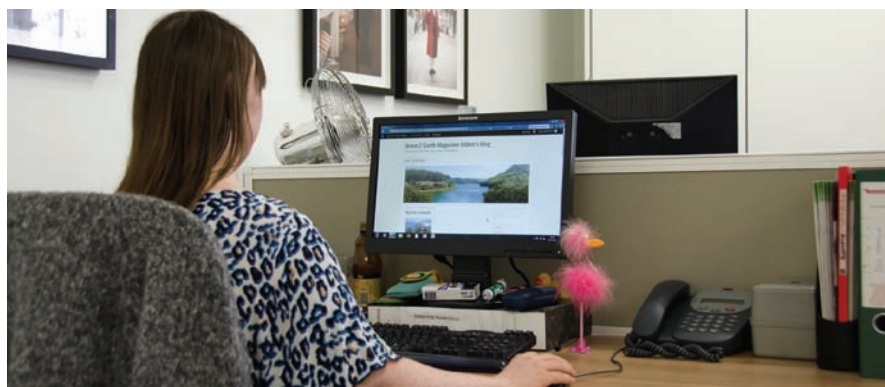
Whilst readers enjoy the magazine, there are still ways we felt it could be improved. Primarily, we wanted the magazine to be more engaging, professional and interactive. After some initial research, we took our ideas to our Down 2 Earth focus group of adults with Down's syndrome, giving us a clearer idea of what Down 2 Earth magazine readers would like to see. We showed the group a variety of magazine designs and asked them to choose their favourites. The group told us that they wanted the magazine to be clear, bold and bright, with lots of images and photos. They also wanted to see more content from readers. The group unanimously decided they enjoyed reading other people's stories and articles. Other suggested sections included recipes, sport, interviews, news and poetry. Everyone in the group was very keen on contributing to the magazine, and we came away with a lot of useful feedback.

Using this feedback, Kate Powell and I have developed a new look magazine,

with a wider range of articles and features that we hope our readers will enjoy. A call out for articles on social media produced a flood of interest, and we have received many excellent articles, pictures and letters. The next issue has several exciting new features, including an interview with the actress Sarah Gordy, who has appeared in TV programmes such as *Call the Midwife*; a reader recipes page; a feature from DS Active; news updates and much, much more.

By now, the September issue of Down 2 Earth Magazine is landing on the doorsteps of DSA member's with Down's syndrome. We hope our readers enjoy the magazine, and we will be seeking feedback on the changes. The editor, Kate Powell, has come up with a brand new slogan to suit the new look magazine – "have your say". We think the magazine should allow readers to do just that.

Kate Powell's new blog



As well as updating the magazine, you may have seen from our social media feeds that Kate Powell has started her own blog. Kate writes a new blog every Wednesday, which is all about her life and what she has been up to. Kate has this to say on her blog:

"I am very passionate about my blog. I love writing it every week. The best part is posting great photos on the blog. I tell everyone I know all about my blog, and it is great to get so many nice comments."

Kate's blog has already reached many readers from across the world, with over 3,000 views in over 55 countries. You can read Kate Powell's blog at: down2eartheditorsblog.wordpress.com

Down 2 Earth Blog

After being inspired by Kate's blog, the London Down 2 Earth group are starting their own blog too! You can read the blog at: down2earthgrouplondon.wordpress.com

Shhhhhh... ■ ■ ■

A sneak peek into the secret world of social media.

By Sarah Hoss

Social Media (Facebook, Twitter, blogging, Pinterest, LinkedIn etc.) – or ‘Shmedia’ as I like to call it – is saving Down’s syndrome.

That’s a very bold statement. Stay with me, and I will show you how. But first, a little personal history.

I was holed up in a leaky caravan in Wales when I first began searching online for information about Down’s syndrome. I was involved in a restoration project at the time. As a family we had a temporary caravan base for work and living space. Outside I was growing my own vegetables and keeping livestock. Sounds idyllic? I found it very tough.

That early information was mainly scientific papers that had been shared online, medical infographics showing scary looking images of “typical features of Down’s”. It wasn’t a good start. I felt terribly isolated.

However, I found a world authority on DS and eyesight based in relatively nearby Cardiff – and dropped her an email. Dr Maggie Woodhouse, familiar to many as the ‘eye doctor’ at Cardiff University has not only assisted our offspring with her expertise, but has also promoted positive images of young people with DS and involved scholars from all over the world to participate in her research.

As part of their studies, they get to meet my son and many other young people with DS and go home with a much broader understanding of the condition and a love for the people they have helped.

During my son’s life, the development of the worldwide web has put parents into direct contact with the medical profession and those enlightened professionals willing to engage directly with us.

But then something new happened. Us, as parents, started creating, not just reading, the expert content. And we changed it. Google “Down syndrome” now and you are more likely to land on a page showing a gorgeous child with DS modeling in a fashion catalogue as

you are to land on a medical page full of upsetting statistics.

I’m not against information, but many mums (on social media sites) have reported the appalling way in which the news of their child’s diagnosis was communicated and this can set a negative tone in those early days.

Thanks to social media, this is being challenged and the parents are doing it for themselves. Recently a delighted young couple announced the arrival of their baby via a dedicated twitter feed.

They knew their unborn had Down’s syndrome and they wanted to keep their big community of supporters updated. The story ended up in the national press. They created a hash tag (useful for following stories on Twitter) ‘Princess Batman’ – ‘So much cooler-sounding than Down’s Syndrome Baby” as the proud mum explained. Twitter was all a-flutter. I remembered the contrast of my own experience. The delivery-room silence that met the birth of my own son nearly 14 years ago was deafening.

When my son was at primary school, Facebook came along and I set up a profile for Geraint to more easily share information with school. I thought it would be helpful, and loaded up lots of information and photos for them to access. Unfortunately it turned out Facebook was banned and his teachers at the time had no access to the Internet. Social and educational services are still struggling with their social media policies but in the future I am convinced that digital tools will be lifelines for our young people.

Douglas Carswell MP in his book *The End of Politics and the Birth of iDemocracy* recounts how an army of parents used to fill up his surgeries asking for help with their disabled children. One day they stopped coming. Were there no more young children with

disabilities in his constituency? No – the stream of anxious parents had dried up because they had all joined Facebook and were now advising each other without the need to take their individual issues to him.

As soon as they arrived, I had no hesitation in engaging with DS groups online.

It was through one of these groups that I became aware of a parliamentary investigation chaired by Fiona Bruce MP into the current abortion laws that allows abortion of babies with DS up until full-term, something I’ve never understood.

Grateful for the opportunity to be heard, I felt proud that my written evidence was included in the report that went to Parliament asking for the law to be changed.

We were one of a couple of British families contacted by a Japanese journalist through shmedia and then hosted the journalist here at my house (yes, we have progressed from the caravan to a proper house).

It is thanks to these groups that I finally did make my way back to the DSA and subscribed. I then saw how much the organization had moved on and started engaging with it properly. Shmedia brought me full circle.

Ideas and campaigns ‘trend’ on Shmedia every day – such as wearing colourful socks to promote World Down Syndrome Day, or when a TV programme is shown that features a storyline involving actors with Down’s syndrome.

There are also occasional campaigns that are promoted via shmedia such as change.org – a petition service. One recent petition regards the plight of a London school boy with Down’s syndrome who was apparently arrested

it's all on Shmedia

And how it's saving Down's syndrome

for entering an open window of his school on a Bank Holiday to collect his favourite hat. Over 100,000 people signed a petition asking for his criminal record to be withdrawn. In the past, this family would have felt utterly powerless. Now they have 100,000 people behind them.

Postings and replies can go on for many days, involving hundred of comments. I've watched in absolute amazement, as mums post details of their child's progress in hospital, on occasions seeming to go to the very brink of death before heading onto the road to recovery and that child turning into a bouncing toddler.

We've also shared the heartbreak of families losing a child and 'gaining wings' and read the heartfelt posts of grieving parents. There are baby pictures, shots taken at school and in the park, family pictures, prom and even wedding pictures. These real stories, being documented on a daily basis, are saving Down's syndrome by bearing witness to the authentic lives being shared.

I recently reached out to this community when dealing with a personal situation regarding the attendance of my son at a family wedding. Within 24 hours of posting, I was deluged with several hundred thoughtful messages. That support, at a time when I felt upset, got me through.

Companies, organizations, and charities: (such as the DSA and DSI – Down Syndrome International) have been quick to embrace this information revolution and are also present.

Many do not allow contributors to directly post onto their pages. To have a contribution published on such a page, one has to write to the organization (via a direct message on the shmedia site or via email) and wait for one of the admin team to post on your behalf. This sort of approach is common among funded organizations taking a cautionary approach to their social media engagement where they like to arbitrate the conversation and be the conductors if you like.

Posts that are shared on these pages

attract a massive response – photos will be acknowledged (by clicking the 'like' button) by thousands of Facebook users, providing an enormous boost to those featured. Bloggers and professional pages (such as Saving Down Syndrome, based in the USA; Circle 21, populated by posts from families all over the world;) tend to be more open to interaction.

There are many 'mummy bloggers' (sometimes dads) sharing their journeys on open pages and attracting a huge following. Some become campaigning and influential such as the excellent Downs Side Up; Down's Syndrome – Raising Awareness and Shifting Attitudes and 'Lose the Label' pages.

Lose the Label is a campaigning page that has a very simple strategy – to promote person first language by putting a message onto contributed photographs of people with Down's syndrome stating the person's name with the message 'I have Down syndrome. I am not Down syndrome'. This page has seen images shared and re-tweeted many thousands of times.

Dig a little deeper and you will find private groups to join (such as Down Syndrome and Autism, Down Right Perfect, Parker's Place, Future of Down's and FoD Pregnancy Support). These are the truly self-organizing, crowd-sourcing groups, usually private, administered by a small group of volunteers.

Not for the faint-hearted, debates can become passionate. These groups are full of the most riveting content. Couples with a pre-natal diagnosis or having been told they are in the high risk category following scans and blood-tests join to find out the truth about life with a child with DS, and some, better informed, go on to share their baby pictures and thank the group for reassuring them when they were making tough decisions.

Against the prevailing culture of pre-natal testing and the promotion of abortion, this social media revolution is saving Down's.

Sarah Hoss works in education and social media as a community engagement specialist looking for digital means to better involve people in decision-making.



The Label campaign featuring Geraint, Sarah's son. Original photo by Sarah Hoss

For those claiming ESA

Are you receiving everything you are entitled to?

By the DSA Benefits Advisers

If you have been moved onto Employment and Support Allowance (ESA) from Incapacity benefit, it may be worth checking the amount of money you receive. You may be entitled to an extra top up or two.

This is because there are two types of ESA: contribution-based ESA and income-related ESA. People who transferred to ESA from Incapacity Benefit were moved onto contribution-based ESA, at least for the first year. However, you can be entitled to both types of ESA, and income-related ESA may entitle you to more money, on top of your contribution-based ESA.

If you are on contribution-based ESA and you find that income-related ESA would award you more, then you can ring and ask for it to be topped up with income-related ESA. You would have to give information about the income and savings of the person with Down's syndrome.

People who apply directly for ESA who have not been on Incapacity Benefit are usually assessed for both types of ESA when they make their claim. Even so, check that you are getting the right premiums if you qualify for income-related ESA.

What is the difference between contribution-ESA and income-related ESA?

Contribution-based ESA is linked to National Insurance contributions. It is not means-tested. People transferring from Incapacity Benefit were put on contribution-based ESA for one year (if they were placed in the work-related activity group) or indefinitely (for those who were placed in the support group).

Savings and other income do not affect contribution-based ESA. However you will not automatically qualify for free prescriptions, eyesight tests etc. You can apply for a reduction or total exemption certificate through the low income scheme on a HC1 form to help with these costs.

Income-related ESA is, as the name suggests, means-tested.

Anything over £16,000 in savings will stop your entitlement to income-based ESA altogether until your savings are reduced. Savings between £6,000 and

£16,000 will reduce the total amount you receive on a sliding scale. Other income is also taken into account.

If you get income-related ESA you will qualify for free prescriptions and maximum help with other health costs such as dentists and opticians.

Enhanced disability premium and severe disability premium

These are the two top ups which are available with income-related ESA, as long as you pass the means-test.

You qualify for the enhanced disability premium of £15.55 per week if you get:

- Higher rate of Disability Living Allowance (DLA) care component, or
- The enhanced rate of Personal Independence Payment (PIP) daily living component, or
- You are in the support group of ESA

You qualify for the severe disability premium of £61.10 per week if you get:

- Middle or higher rate of DLA care component
- Personal Independence Payment daily living component
- No one gets Carer's Allowance for looking after you
- You technically count as living alone.

You may count as living alone even if you actually live with other people. For example, other people who also get the benefits listed above are ignored. So someone living in supported living may count as "living alone". Other people who are joint tenants are also ignored. Get advice if you think you may count as living alone.

Examples

I live with my parents and I am in the work-related activity group of ESA and I also get the higher rate of the DLA care component. I don't have any savings or other income.

Someone in receipt of ESA with savings below £6,000 should receive a personal allowance of £72.40 plus the work-related activity component of £28.75 and also the enhanced disability premium of £15.55 for a total of **£116.70 per week**.

I live at home with my family and I have been put in the support group of ESA and I get middle rate DLA care component.

You should get the basic allowance of ESA of £72.40, the support component of £35.75 and also the enhanced disability premium of £15.55 for a total of **£123.70 per week**.

I am in supported living and I receive the standard rate of PIP daily living component and have been placed in the work-related activity group of ESA. No one claims Carer's Allowance for looking after me. I have a small inheritance of £3,500.

You should get the basic allowance of ESA of £72.40 and the work-related activity component of ESA of £28.75 per week. You can't get the enhanced disability premium of £15.55, since you are not on the enhanced rate of PIP, nor are you in the ESA support group. However, since you live in supported living with other people who receive disability benefits, you count as living alone and are entitled to the severe disability premium of £61.10. This adds up to **£162.25 per week**. Your inheritance will not be taken into account as it is below the £6,000 threshold.

Council Tax Discount Scheme

This information may be especially relevant if you live with your adult son or daughter with Down's syndrome, as you may qualify for a discount on your council tax. There has been a recent change to the rules, so more families may get a discount.

The discount scheme allows a discount on council tax where there are less than 2 adults living in a dwelling. An adult is someone aged 18 and over.

If only 1 person over 18 lives there, the discount is 25%. If no one lives there, the discount is 50%. BUT some people are disregarded. They are not counted even though they actually live in the dwelling.

What's changed?

People with Down's syndrome have usually been disregarded, and this hasn't changed. So, for example, if you live with a son or daughter over 18 who has Down's syndrome, and there is no other adult in your household, you may already be getting the 25% discount.

What's changed is the rule about disregarding carers. Until now, carers of people aged over 18 were only disregarded if the person they cared for got the higher rate of the care component of Disability Living Allowance

(DLA). From now on, carers of people aged over 18 who get the middle or higher rate of the DLA care component, or either rate of Personal Independence Payment (PIP) may be disregarded, as along as they meet the other conditions.

The disregard for someone with Down's syndrome

People with Down's syndrome are disregarded under the following rules

Someone with a learning disability is disregarded for council tax if:

- They have a "severe impairment of intelligence or social functioning (however caused) which appears to be permanent; and
- Have a certificate from a registered medical practitioner confirming this (which may cover a past, present or future period) and
- Are entitled to one of the following benefits:
 - DLA middle or higher rate care component
 - PIP daily living component (either rate)
 - Employment and Support Allowance
 - Incapacity Benefit
 - Severe Disablement Allowance
 - Income Support including a disability premium
 - The disability element of Working Tax Credit
 - (and others, not likely to be relevant to someone with Down's syndrome)

Note that for council tax disregard, people with Down's syndrome are routinely considered "severely mentally impaired", even though this is not in line with other evaluations for health or education, or in fact, other benefits!

The disregard for carers

Note that you do not have to get Carer's Allowance to count as a carer.

Carers are disregarded for council tax if:

- They provide care for at least 35 hours a week on average
- They are resident in the same dwelling as the person cared for
- They are not the partner of the person cared for
- They are not the parent of the person cared for, if the person cared for is aged under 18. NB. This means that if your child is under 18, you **cannot** be disregarded as a carer. You can only be disregarded once your child is over 18
- They care for someone who is entitled to one of the following:
 - the middle or higher rate of DLA care component;

- either rate of attendance allowance or constant attendance allowance; or
- either rate of personal independence payment daily living component.

Paid carers can also be disregarded under certain circumstances.

More than one person in the same dwelling can count as a carer, including where caring responsibilities are being shared.

If there are more adults in the household, other than the person with Down's syndrome and their carers, check to see if any of them can also be disregarded. For example, students are disregarded.

Examples

Sally is 24 and lives with her mother Joanne. She has Down's syndrome and gets Employment and Support Allowance (ESA) and DLA care component at the middle rate. Joanne has a part time job, but she cares for Sally 5 days a week.

For council tax, Sally is disregarded because she counts as someone with a severe permanent learning disability. Joanne gets a doctor's statement confirming this. Joanne doesn't get Carer's Allowance, but she is also disregarded as Sally's carer. In this household, both adults are disregarded so Joanne gets a 50% discount on her council tax.

Joanne only found out about the discount scheme recently. She can ask the council to backdate a 25% discount to Sally's 18th birthday when Sally was able to be disregarded, and to backdate the 50% discount to when the new rule disregarding herself as a carer of someone on DLA middle rate care component came into effect.

Rashid and Bushra live with their 31 year old son Amrit, who has Down's syndrome and gets the higher rate of the DLA care component and is in the support group of ESA. Bushra's mother, who has dementia, also lives with them. Rashid works full time, while Bushra cares for her mother and for Amrit. Their 23 year old daughter who is a student at university comes home outside term time.

Although there are 5 adults in this household, they will be eligible for a 25% discount, since Amrit and his grandmother, Bushra and her daughter (a student) are all definitely disregarded. If Rashid also cares for over 35 hours a week during the evenings, nights and at weekends, he can also be disregarded as a carer, and they would be eligible for a 50% discount.

Remember to ask for backdating if you find you have been eligible for a discount for some time, but didn't claim it.

Employment and Support Allowance (ESA) Survey

In October 2013, we put a survey asking about people's experiences of ESA on our website.

Twenty one people responded to the survey, and although the number is small, the findings in general confirm the anecdotal evidence from benefits advice calls received by the DSA about how ESA is working for people with Down's syndrome.

Overall, most people with Down's syndrome are not encountering problems when claiming ESA.

Three quarters of responses rated the experience of the claiming process as excellent, good or satisfactory, with 95% (that is, 19 people out of the 20 who responded to this question) saying that the claim was successful. 90% of claimants were put in the support group, with only 2 out of the 20 who responded being put in the work-related activity group. 90% of responders (18 out of 20 people) felt that the claim had resulted in the person being placed in the correct group.

Interestingly, 75% of people had not been called to a face to face assessment. However, of the 5 cases where a face to face assessment had happened, three rated the experience as poor or very poor.

Although the majority of people are not experiencing difficulties, it is still worrying to note that roughly 25% of responders report negative experiences of the claim process or the outcome.

We're pleased that when asked about their experience of contacting the DSA for information and advice on benefits, 9 of the 10 people who responded to this question rated our service as excellent (7), good (1) or satisfactory (1). However, we are still concerned that one person rated us as very poor.

55% of people did not seek information or advice from any advice agency about their ESA claim.

We should not put too much emphasis on these results, given the small sample, but they do indicate that though the majority of claims are trouble-free, a sizeable minority have difficulties. For the full results, go to "ESA survey October 2013" in the Benefits News section on our website, or contact us for a paper copy.

If you have any questions or need more information, please contact the DSA benefits advisers, Chris and Helen, on 0333 12 12 300, Monday to Friday, 10-4.

The Mental Capacity Act

Decision-Making and the Law

By Vanda Ridley, Communications Manager and Amy Deakin, Information Officer

Making choices is a part of everyday life. However, people with Down's syndrome may need support to make a decision for themselves.

For families, questions about the law around support, choices and mental capacity can seem complex and confusing. Recent evidence from the House of Lords Committee looking at the Mental Capacity Act found that people were overwhelmingly in favour of the Act and Code, but that work still needed to be done around raising awareness of what it has to say.

The DSA has been working on providing clear information on mental capacity, so that families have a better understanding of the law and what it means on a practical level.

Understanding mental capacity

Mental capacity is the ability to make decisions. If someone lacks mental capacity, they are assessed as unable to make a particular decision for themselves. These decisions can range from choosing what clothes to wear to major life choices, such as deciding where to live. According to the Mental Capacity Act, there must be no 'blanket decision' made about an individual's capacity. A person's mental capacity is always assessed on a decision by decision basis.

Introducing the Mental Capacity Act and Code of Practice

The Mental Capacity Act sets out how to help people make their own decisions wherever possible. It also says what should happen if someone is unable to make a decision for themselves. It applies to anyone over the age of 16 living in England and Wales. The Mental Capacity Act makes clear that each individual is assumed to have the capacity to make a decision unless it can be proved otherwise. The Act is supported by a Code of Practice with

specific guidance on how the law should work in practice.

Why is the Mental Capacity Act important for carers and families?

The Act aims to look after the best interests of people who lack capacity and encourage those who know them best to work together in achieving that. Being aware of the Mental Capacity Act can help families support their son or daughter make a decision. If they cannot make a decision, the Act and Code can also help families ensure that any decision about their son or daughter's life is made in their son or daughter's best interests, and that they are as a family are included in such a decision.

Key principles of the Mental Capacity Act

The Act has five key principles to guide carers who have concerns over someone's capacity to make a decision:

- Every adult has the right to make their own decisions if they have the capacity to do so. Family carers and healthcare and social care staff must always assume that a person has capacity to make a decision unless it can be established they do not.
- People must have support to help them make their own decisions. This principle is to stop people being automatically labelled as lacking capacity just because they have a learning disability. Types of support could include using alternative forms of communication, providing information in different formats (e.g. photographs, drawings, tapes) or having a structured programme to improve a person's capacity to make particular decisions (e.g.

a healthy eating programme.)

- People have the right to make decisions others might think are unwise. They may need further support to help them understand the consequences of their decision.
- Any decision made on behalf of someone must be made in their 'best interests'. The person themselves and those who know them best must be involved in the decision-making.
- A person making a decision on behalf of someone must always ask themselves if there is another option that would interfere less with the person's rights and freedoms.

Assessing a person's mental capacity

According to the Mental Capacity Act, a person has the mental capacity to make a decision if they can do all these things:

- Show **some understanding** of the information given to them. It is very important that they are given the relevant information in the appropriate format and time to understand it before any decision on their capacity is made.
- **Retain that information** long enough to be able to make the decision. Notebooks, photographs, posters, videos and voice records can help people record and retain information.
- **Weigh up** the information and use it to make a decision.
- **Communicate** their decision. This could be by talking, using sign language or other communication aids, blinking or squeezing a hand.

When a person lacks capacity: acting in a person's best interests

If someone lacks capacity to make a particular decision, the Act says the decision must be made in their 'best interests'. This simply means that any decision made must be in the interests of that person. That is the same for whoever is making the decision, including a parent or carer, a social worker, or another professional. It is the same for every decision, no matter how big or small.

The person who has to make the decision on behalf of someone who lacks capacity is known as the 'decision-maker'. If your son or daughter lives at home, you will probably be the decision maker for any day-to-day decisions. For bigger issues involving social care or health matters, the decision maker will be a professional who should have expertise in the Act. However, families should not be excluded from these decisions.

Ways to help your son or daughter have their say if they don't have mental capacity

If your son or daughter does not have the mental capacity to make a particular decision, there are ways to include them in decisions about their lives:

- Start thinking and talking about the future as a family. If your son or daughter is under 18, the 14+ transition review is a good time to begin finding out about what is available (e.g. care and support, work, leisure, housing).
- A person centred plan can help your son or daughter have their wants and needs listened to. A person centred plan focuses on a person's interests, needs, dreams and desires. This can help professionals understand the wishes and needs of your son and daughter.
- Circles of support can also provide an extra layer of support. A circle of support is a group of people who know a person well, such as family, friends and supporters, who meet regularly to help the person they support achieve what they want. You can find out more about circles of support in the DSA mental capacity factsheet.
- Keep a written record of what works and does not work for your son or daughter. If you do not agree with a 'best interests' decision made by a social or health care professional, this record will provide valuable evidence.

If a best interests decision goes wrong

Sometimes families are unhappy with the outcome of a 'best interests' decision. Common issues raised by families tend to include the way social care, healthcare and other such professionals make decisions about their son or daughter.

When disagreements occur, it is usually best to try and settle them through discussion, before they become serious. If you have concerns about a decision being made on behalf of your son or daughter, it is perfectly acceptable to check if a 'best interests' process has been followed. Talk to the professional or put your concerns in writing, asking for evidence of:

- An assessment of capacity to make this particular decision.
- Your son or daughter's involvement in the decision.
- Consideration of your son or daughter's wishes and feelings.
- Consultation with the right people.
- A written record of the process used to determine your son or daughter's best interests.

If this does not resolve your concerns, there are things you can do. You can:

- Involve an independent advocate. This is not an Independent Mental Capacity Advocate. Your local authority or citizens advice bureau should be able to help you find one locally.

- Provide written evidence to support your challenge to the decision. This could be a person centred plan or from a circle of support.
- Use the formal complaints procedure for the statutory body involved (health, social care).
- If you can't resolve the issue through a formal complaint, the Health Service Ombudsman or the Local Government Ombudsman (in England) or the Public Services Ombudsman (in Wales) may be able to investigate.
- Seek advice from the Office of the Public Guardian.
- Make an application to the Court of Protection.

Further information on mental capacity and the Mental Capacity Act

The DSA has recently produced a factsheet to provide you with further information on mental capacity and decision making. You can download this factsheet from our website.

Please contact the DSA Information Officers if you have any further questions.

The helpline is open Monday – Friday, 10 – 4pm.

Alternatively, you can email at info@downs-syndrome.org.uk.

In Memoriam

Harry Whitaker | 11 February 2011 - 1 July 2014

Harry Whitaker very sadly passed away on 1 July 2014 at Leeds General Infirmary whilst being cuddled by his Dad and being told how much he was loved by his Mum.

Harry was a massive part of his family, filling his home with laughter and love, if not a little bit of chaos at times. His sisters Maisy and Martha totally idolised him.

Harry was also a big part of a wider community as he was also part of the cast of ITV's soap drama Emmerdale. By being part of the cast, Harry educated people about

Down's syndrome and family life whenever he was on screen.

Harry and all who were lucky enough to know him well are left with beautiful memories of a lovely little boy who really made his mark during his short life.

The Down's Syndrome Association extend our condolences to his family who miss their little family boss.



Prisca

Photography by Mariana Melo Lima





It's 2pm on a relaxed Saturday afternoon in Northolt. Sixteen year old Prisca is at home.

She smiles while selecting her dresses, trying on necklaces and earrings. All these items are colourful and feminine. Dispensing with having to wear her Belvue uniform leaves her excited, although she really enjoys going to school.

"Music is my favourite module. I love singing and dancing."

From the sofa, Tee, her mother, exclaims how beautiful she looks and takes some snaps with the phone. There are pictures of Prisca all over the house, on the walls and on the shelves.

Prisca is ready. Whenever my camera points at her, she immediately smiles.

After a few clicks, she asks to change clothes and to search for a new place. Her nephew Torrel joins her in the photographs.

At one point, Prisca brings out Lizzie, her favourite doll since she was two. She holds Lizzie carefully. Her plans for the future include being a nanny as well as taking care of her mother.

"When my mother is not feeling well, I cook for her and I help her clean the house."

"She is loving, intelligent and very friendly" – says Tee. Prisca's enthusiasm never slows down throughout the afternoon.

"I'm going to be in a magazine", her eyes filled with joy give me a very strong inner happiness.



Mariana Melo Lima is a freelance professional photographer currently working on several projects for the Down's Syndrome Association. She is interested in documentary photography and has been working on a project for a year photographing couples with Down's syndrome who are in a relationship. She has installed a new gallery for the Langdon Down Museum which includes her photographs and those from the Shifting Perspectives exhibition. In the Spring she worked on a project for the Bethlem Royal Hospital Archives and Museum. Mariana specialises in portrait photography with adults, children and families. Contact Mariana at: marianamelolima@gmail.com | www.marianamelolima.com

Who really decoded Down's syndrome?

Nic Fleming

The following article is reproduced with kind permission of New Scientist and first appeared in magazine issue 2963 5 April 2014.



Photograph by Rodolphe Escher

The Frenchman credited with finding the genetic cause of Down's is in line for sainthood. Now his colleague says it was her who made the crucial breakthrough.

In a nondescript hotel room on the outskirts of Bordeaux, an elderly lady puts on a smart white skirt and top and applies lipstick. Today is a special day for 88-year-old Marthe Gautier. She has been invited to speak at a prestigious scientific conference, after which she will receive a medal acknowledging her part in one of the most important medical discoveries of the 20th century.

It is to be her moment of vindication, but it never arrives.

Earlier that day, two legal representatives turned up at the French Federation of Human Genetics conference bearing a court order allowing them to record her talk. They looked at Gautier's slides and pointed out sections that they said could be defamatory.

Fearful of legal action, the organisers decide to ask Gautier to stay away. Two of them are dispatched to the

hotel where they unceremoniously hand over her medal, still in its red box. Her talk is cancelled.

Disputes over scientific credit are common, but few culminate in such drama. The legal representatives were acting on behalf of the relatives and supporters of the late Jérôme Lejeune, a geneticist, paediatrician, anti-abortion campaigner, friend of Pope John Paul II and current candidate for sainthood.

Lejeune is not well known in the English-speaking world, but in France he is a scientific legend. In 1959, he was the first author on a brief research paper revealing the cause of Down's syndrome to be the presence of an extra chromosome. It was the first chromosome abnormality discovered in humans, and marked a breakthrough in our understanding of hereditary diseases.

Gautier's name is also on that paper. But for decades her part in the discovery was a mere footnote. Now, more than 50 years on, she has made an amazing claim: the crucial breakthrough was her's, not Lejeune's.

His supporters reject her claim and argue she lacks evidence to back it up. Others, though, are rallying to her cause, comparing her to Rosalind Franklin, the British biophysicist who many believe should have received greater recognition for her work on the structure of DNA.

Fighting spirit

A few days on from the events in Bordeaux, I visited Gautier in her Paris apartment around the corner from the Moulin Rouge. She is in a combative mood, perhaps buoyed up by the bunches of flowers from well-wishers that jostle for space in her entrance hall. "The organisers asked me not to speak to avoid legal problems," she says. "But I should have refused and given my talk anyway."

This fighting spirit perhaps helps explain how a woman from a modest background with no connections was able to advance within the hierarchical and male-dominated world of medicine in 1950s France.

Gautier was the fifth of seven children born into a family of farmers. She attended a Catholic boarding school in Lille and in 1942 followed in the footsteps of her oldest sister, Paulette, who was studying medicine in Paris.

Paulette was killed by retreating German troops in 1944, but not before giving Marthe some advice.

"She told me that as we don't have a father who is a doctor, and we are women, we have to work twice as hard as men to succeed," says Gautier.

"So that's what I did."

Gautier became a doctor and in 1950 won a prestigious medical internship – one of only two women among 80 successful candidates. In 1955 she went to Harvard University to learn new techniques for treating rheumatic fever and related heart disease in children. While there she was given a part-time job as a technician in a cell-culture lab, where she learned how to grow human cells in a dish.

Chromosome count

When she returned to France, a job she had been promised had been given to a colleague. So she reluctantly took a poorly paid teaching position under Raymond Turpin, renowned head of the paediatric unit at the Trousseau Hospital in Paris. It was here that she became interested in human chromosomes.

Turpin had a long-standing interest in Down's syndrome; in 1937 he hypothesised that it was caused by a chromosome abnormality. But in those days techniques for analysing chromosomes were lacking.

In autumn 1956, however, that changed. Turpin returned from a genetics conference with exciting news – scientists in Sweden had perfected a technique for viewing human chromosomes under the microscope. As a result, the count was now known to be 46, not 48 as previously believed.

To Turpin that meant it should now be possible to count chromosomes from somebody with Down's syndrome.

"Professor Turpin said to us, 'it's a shame that no one in France knows how to do cell cultures'," recalls Gautier.

"I replied immediately, 'If you want, I'll do it, if someone lends me a laboratory'."

She was given access to a lab with a fridge, a centrifuge and a microscope. She had two technicians to help her but the work was unpaid and she even took out a loan to pay for glassware.

She also had to source supplies which were not available in France.

"I went to the countryside in my 4CV and returned with a cockerel which took up residence in the garden of a nurse. I used plasma from the cockerel to immobilise the tissue samples. To provide the serum needed as a nutrient, I took my own blood."

For 10 months, Gautier taught herself to culture normal human cells and count the chromosomes.

"I verified that the cells had 46," she says.

Then came the big break.

"Eventually, I received a sample from a child with Down's syndrome. When I counted 47 chromosomes, I was alone but I shouted out 'yes!'."

At this stage, May 1958, Gautier admits she could not be absolutely sure what she was looking at. She did not have a photomicroscope to take pictures of the chromosomes and confirm the presence of an extra one. But as luck would have it, she had begun receiving visits from a certain Jérôme Lejeune, head of the Down's clinic at the hospital. He had trained under Turpin and was now researching the hereditary basis of the syndrome.

"Lejeune offered to get the photos done elsewhere," says Gautier. "I said 'ok,

take the slides and bring me back the photos'. He took the slides. I never saw them again." She adds that when she asked about them, Lejeune said they were in Turpin's office.

Another sample from a boy with Down's was cultured in June. The cells also had 47 chromosomes.

Then things started to turn sour. In August 1958, Lejeune presented the findings to the International Congress of Genetics in Montreal, Canada – a move Gautier says she wasn't consulted about. Following results from a third case in December, Turpin gave his go-ahead for a publication in the journal of the French Academy of Sciences (Comptes Rendus, vol 248, p 602).

Gautier says she was excluded from the process and only saw the paper two days before publication.

"I came to Trousseau one Saturday morning and I saw Lejeune. He had the paper in his hands and he told me it was to be published on Monday. I looked at it, and I saw the order of authors: 'Lejeune, Gautier, Turpin'. I was shocked. I worked all that time, and it's Lejeune who is first?"

To add insult to perceived injury, her name was wrongly spelled "Marie Gauthier".

Lejeune was also first author on a second paper published in March 1959. Soon after, Gautier left the team to resume her work on the treatment of paediatric heart problems.

Lejeune, meanwhile, went on to receive pretty much every award going, short of a Nobel prize. In 1962 President Kennedy presented him with the first Kennedy Prize for his "discovery of the cause of Down's syndrome". Two years later a professorship of fundamental genetics was created for him at the Paris Faculty of Medicine; in 1969 he received the William Allan Award, the highest accolade in human genetics.

Despite his success, Lejeune was troubled by the implications of the work. As a member of the traditionalist Catholic organisation Opus Dei and a vocal opponent of abortion, he disliked the fact that it had laid the groundwork for prenatal testing and termination of pregnancies. He believed that this stance cost him a Nobel, but it did earn him the friendship of Pope John Paul II.

Following Lejeune's death from lung cancer in 1994, the Jérôme Lejeune Foundation was set up to continue his work.

After interviewing Gautier, I travelled across Paris to meet the foundation's executive director Thierry de La Villejégu. He is a large, jolly man who is in no doubt about the legitimacy of Lejeune's claim.

"He received the cell culture preparations of Marthe Gautier and he was capable of breaking apart the chromosomes, of enlargement of the different chromosomes and of observing a 47th chromosome," he says. "Lejeune was involved at each stage, and he was especially involved in providing the first detailed documentation of a preparation with 47 chromosomes."

As evidence, de La Villejégu produces a letter Turpin sent Lejeune on 28 October 1958. It states:

"Two visitors who came to see me, Cordero Ferreira (a paediatrician from Lisbon), and J Mohr from Oslo, were amazed by your chromosome preparations [emphasis added]. Madame Gautier and Madame Massé [a technician] are still on 46."

I also meet the foundation's director of research, Valérie Legout. When I ask her whether Lejeune was right to put himself first on the paper, she says that was how things were done then.

"We shouldn't try to rewrite history, rather we should respect the decision made at that time."

De La Villejégu also defends this decision.

"There is currently a revisionist climate to denounce the supposed sexism of men at that time and victimisation of women," he says. "It's a revisionist aberration which leads to the reinterpretation of history."

De La Villejégu continues:

"All our documents talking of the discovery say Lejeune, Gautier, Turpin. If by chance Gautier and Turpin are missing it's the foundation's mistake; it's not intentional."

I checked. Two pages of the foundation's website credit Gautier and Turpin but in most instances Lejeune is referred to as the discoverer, without acknowledgement of anyone else.

Smoking gun

Gautier is dismissive of the foundation's story. Regarding Turpin's letter, she points to one Lejeune sent her a few days later that suggests Turpin had misunderstood whose work he was looking at. Dated 5 November 1958, it states:

"A recent note from the boss [Turpin] told me that your preparations impressed Mohr, the Norwegian geneticist [emphasis added]."

Much of the dispute appears to hinge not so much on who did what, but on the relative importance of the different roles. Lejeune's supporters seem to accept that Gautier adapted the technique and carried out the cell culture. Once she thought she had seen 47 chromosomes, Lejeune produced enlarged images of them, revealing that the anomaly was an extra copy of what we now call chromosome 21. His supporters say this was the key to the discovery.

In the absence of a smoking gun, I asked some people who are well placed to judge.

Peter Harper, a retired medical geneticist at Cardiff University, UK, interviewed many of the pioneers of cytogenetics for his 2006 book *First Years of Human Chromosomes*.

"You'd probably have to do quite a bit of work to get decent photos, so I wouldn't say Lejeune's contribution was negligible. But if there was a single moment of discovery it would have come before that – looking down the microscope."

Another Gautier supporter is Patricia Jacobs, professor of human genetics at the University of Southampton, UK, who was a rival of the Paris team in the late 1950s.

"Marthe Gautier has been treated like rubbish," she says.

"Counting chromosomes is easy: if you have good quality preparations, you just have to look down a microscope. Jérôme Lejeune took her work and published it with his name at the top."

For Harper, there is a sense of déjà vu.

"What is so striking is that a highly able, highly trained person with considerable research experience was subsequently regarded as a technician. I met this again and again. The parallel with Rosalind Franklin is particularly apt because in each case they had materials which were critical which they were parted from, either inadvertently or otherwise."

Why now?

One obvious question is why Gautier waited so long to tell her side of the story. She says she planned to keep her counsel until after her death, but was provoked by the campaign to have Lejeune canonised – which started in 2007 – and the 50th anniversary of the discovery in 2009. As a result of these, ever more dramatic claims were being made about Lejeune's virtues while ignoring the contributions made by others.

"I began to realise that if I didn't correct the record my efforts would not be recorded historically," says Gautier.

"The Lejeune Foundation was constantly stating, and still constantly states, that he was the discoverer. I started to get annoyed because I'm going to die soon, and if it continues I'll be forgotten."

In 2009 she published her account in the French journal *Médecine Sciences* (vol 25, p 311). An English translation was published in *Human Genetics* (vol 126, p 317).

It was this article that attracted the attention of the Lejeune Foundation and ultimately led to the debacle in Bordeaux.

De La Villejégu claims Gautier's 2009 account contains defamatory statements and that legal representatives were sent to the conference to check whether she repeated them, and to collect evidence for a potential case to protect Lejeune's reputation. French law permits the relatives of the dead to bring defamation cases against those they say are harming their reputations with untrue statements.

If the foundation was hoping to suppress the questioning of Lejeune's role then the tactic has backfired. The resulting controversy has helped spread Gautier's account far beyond the mainly French and academic circles within which it was previously known.

As for Gautier, two weeks after my visit she still wants to see what she believes is an injustice corrected, but the same time is weary of fighting.

"I am proud of what I achieved, but it wasn't all that difficult," she says.

"Scientific discoveries often involve being in the right place at the right time and a degree of luck. But in the end there is more to life than chromosomes. All this fighting is tiring, and I have other things to do."

Nic Fleming is a writer based in London.

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The LGO and you

If you have complained to a council about its service, and you are not happy with the council's response, we may be able to help. We can look at your complaint and reach an independent decision about what has happened. Our service is free, and we look at many complaints involving adults and children with learning disabilities.

When people come to us, they are often frustrated and upset about mistakes that have been made and services they have missed out on. We understand this, and if we cannot help we will explain clearly why this is. There are some complaints we cannot look at – special educational needs (SEN) decisions which you can appeal at a tribunal, for example.

If we find a council has done something wrong, we then look at how this has affected you. We recommend what we think the council should do to put things right. Usually we ask the council to take

action to put you back in the position you would have been in, if nothing had gone wrong. So if a decision which does not have appeal rights has been affected by fault, we may ask the council to reconsider it.

If practical action isn't possible, we may ask the council to make a small payment to acknowledge the impact of its fault. And almost always, we ask for service improvements to make sure the fault isn't repeated. Often, this is what the people who complain to us want most of all.

So, how can we help you?

Statements of special educational needs (SEN)

Most children with Down's syndrome need a statement of SEN. The council should tell you within six weeks of your request for an assessment whether it is going to do one. It shouldn't take more than six months for the council to issue a final statement of SEN. In either case, if it takes longer, we can look at the delay. Sometimes we just need to recommend that the council makes the decision or issues the statement straight away, so you can appeal to tribunal.

Sometimes it can take months or even years to put in place all the provision listed in a statement of SEN. We often see delays in arranging speech and language therapy and occupational therapy. Councils sometimes expect schools to arrange these provisions but it's the council's responsibility to make sure this is done. If we find there has been a significant delay we may ask the council to arrange extra 'catch-up' provision.

There should be a clearly documented annual review of the statement of SEN. If the review recommends amendments the council needs to make a clear decision about whether it will change the statement. If you disagree with the decision you can appeal to tribunal, but you need a decision first! We can help if there has been a delay. And if the delay means your child has missed out on some extra provision, we can recommend the council puts that right.

Reviews are especially important to plan the transfer from primary to secondary school, and the transfer to post-16 provision. There should be a joined-up approach to post-16 transfer that takes account of the need to prepare for independent living as well as progress in academic learning. We investigate cases where councils don't plan this in good time, or don't involve all the right people in the planning.

If the school named in your child's statement of SEN is more than two or three miles from your home, the council normally provides transport to and from school. You can usually take a dispute about this to tribunal. But we can look at problems with the transport itself – for example, if a taxi is consistently late and the council does not sort this out, or if the council refuses to vary the transport so your child can attend after-school clubs.

If there are good reasons why a child cannot attend school, the council has to provide suitable alternative education. Sometimes councils don't do this, or they just provide a few hours a week and don't review the arrangements regularly. We can look at delays and problems in arranging alternative education.

Case study 1

J had a statement of SEN. When her family moved to a new area and J changed schools, the council failed to issue a new statement of SEN for two terms. J missed some provision because of this. We recommended the council fund additional provision for J to make up for what she had missed, and pay her mother £250 to acknowledge the

time and trouble she had spent chasing officers and making her complaint.

Social care

Carers are entitled to have their needs assessed, to see if they can access respite care. We can look at complaints about councils refusing to provide respite care and delaying in arranging it. We can also look at problems with the care provided, and complaints about how the council has investigated allegations of abuse against children and vulnerable adults.

Sometimes things go wrong with the transfer from children's to adult social care services. The transfer should be carefully planned and the council should assess the individual's social care needs in good time. The individual can then have a say on how their needs will be met and choose whether they want to buy their own services through direct payments, or to ask the council to provide services. The council must also carry out financial assessments based on government guidance.

We look at complaints about councils' assessments and if we find there has been a mistake we ask the council to put it right. Effective care planning is essential and we also look at complaints about care planning and about the failure of providers to follow the care plan.

Councils must follow the law to decide if individuals have the mental capacity make choices about their care. If councils do not assess capacity properly, individuals can be unfairly prevented from making their own choices, or they can be expected to make decisions they do not have the capacity to make. We look at both sorts of complaint.

Case study 2

For about 20 years, Mr D, who has Down's syndrome, lived in residential care. He formed a long-standing friendship with another resident, Ms B, and proposed to her. Two different social workers met them over the next few months to talk about their plans. But the council did not assess Mr D's capacity to understand such a decision until two and a half years after he had proposed to Ms B. During that period officers encouraged Mr and Ms B to talk about the details of their wedding and where they would live afterwards. But once Mr D's mental capacity was assessed by a psychologist, the council had to tell Mr D that he could not marry Ms B after all. Mr D and Ms B accepted this decision and were not distressed by it.

We said that the council's failure to consult Mr D's family and to assess his mental capacity early on gave him false

hope that he could marry Ms B; it also led to considerable distress and anxiety for his family. We recommended the council pay his family £500 to acknowledge the impact of its fault, provide more training about mental capacity for staff who work with people with learning disabilities, and consult residents' families much sooner about their relatives' decisions.

Financial support

Many decisions about benefits and financial support carry a right of appeal. But we can look at delays by the council in awarding benefits.

Sometimes families need to adapt the home to meet the needs of a disabled child or adult. We can look at complaints about applying for a disabled facilities grant, and complaints about delays in getting one, or in arranging for the works to be carried out. If the works will cost more than the available grant, and the modifications are for a disabled child, the council should consider other ways of helping the works to go ahead. So we also look at complaints about councils not doing this.

Case study 3

Mrs A complained that the council had delayed arranging to adapt her home to meet her teenage son L's needs. L has Down's syndrome, mobility difficulties, and a medical condition affecting his urinary continence. Mrs A asked for a grant to convert an upstairs bedroom into an en-suite bathroom for L. The council did not take account of information from L's consultants when deciding the adaptations were not necessary.

We found the council had wrongly focussed on whether the adaption Mrs A wanted was necessary to meet L's needs, instead of assessing L's needs and then considering the right way to meet them. We asked the council to carry out a new assessment. It did so and decided Mrs A's home needed a downstairs toilet, and a walk-in shower, to meet L's needs. This was not the adaption Mrs A had proposed but she agreed it was right for L.

More information

You can make a complaint by calling us on 0300 061 0614 or by completing a simple form on-line at www.igo.org.uk.

We publish most of our decisions about complaints on our website. You can search by topic or keyword and this will give you a more detailed picture of the complaints we investigate and their outcomes.

Local Government
OMBUDSMAN



Training at the DSA

2014 - 2015

About the Access Training Team

The DSA Access team has been busy the past few months providing training all over the country. A big part of the Access training programme is focused on how to support babies from birth, through the school years and into early adulthood.

Our Development and Education training days are designed to meet the needs of parents, family carers, education staff and other practitioners.

What's coming up

With the start of a new academic year, we are pleased to present a freshly updated Development and Education training programme. Our events are extending from half to whole days and we are adding new dates to our programme on a regular basis.

We already have several dates confirmed at our head office in south west London and some in the north of England which we will be adding to, so keep an eye on the website for events happening at a location near you.

Other training

Tell it Right, Start it Right

This is our RCM accredited training course for all health professionals involved in every step of antenatal and postnatal care. Launched in 2010, the aim of the day is to equip health practitioners with accurate, balanced and up-to-date information about Down's syndrome which they can use to support expectant or new parents of a baby with Down's syndrome.

Ageing and Dementia

This course is for all carers and support staff involved in supporting an individual with Down's syndrome and dementia. The day focuses on what Down's syndrome is and the link with dementia, recognising the stages of dementia and strategies for supporting those who have received a diagnosis.

Both of these programmes are provided on a bespoke basis; please see below.

For more information

The Access team can provide any of the above training at a time and place to suit you, as part of a bespoke package.

Supporting Early Development (birth to 5 years)

Friday 26 September 2014:
9am – 4pm, Teddington

Supporting Social Development and Behaviour (2 to 11 years)

Monday 20 October 2014:
9am – 4pm, Sheffield

Thursday 12 February 2015:
9am – 4pm, Teddington

Support and Practice in Early Years and Primary Education (4 to 11 years)

Friday 10 October 2014:
9am – 4pm, Teddington

Friday 20 March 2015:
9am – 4pm, Teddington

Support and Practice for Young People in Secondary Education (11 to 16 years)

Friday 21 November 2014:
9am – 4pm, Teddington

Supporting Social Development and behaviour (11 to 18 years)

Thursday 26 February 2015:
9am – 4pm, Teddington

Please have a look at our website for further details on course content, dates, costs and booking information: www.downs-syndrome.org.uk/support-services/training



WorkFit has increased its reach and signed up more employers over the last twelve months.

We have now placed 35 people with Down's syndrome into meaningful work opportunities. We have worked closely with the employers who have joined the programme, taking them through our bespoke support service.

The training gives them a detailed insight into how to work effectively with people with Down's syndrome, making sure that our work placements are sustainable and offer future development. To date we have trained 34 employers.

Our unique approach has led to high praise from our employers, who have said:

A very good positive impact – I now have a lot of knowledge and understanding that I never had before. This was a great session that has given detail in all aspects of how to work with this group of people.

Omega Training Services

Very positive and renewed my commitment.

Travelodge

Thought I knew a lot about Down's syndrome but opened my eyes to the importance of work in their lives – and the extent of their aspirations. I feel that it is very positive and after initial implementation it can be very positive for employer and employee.

Cardiff University

In addition, WorkFit has also provided support to non WorkFit placements, where the individuals were already in employment and were at risk of losing their job. This included troubleshooting, training respective staff and providing advice on reasonable adjustments.

WorkFit

Growth Leads to More Opportunities for People with Down's Syndrome

My son has been working for 9 years but was having problems with one of his employers. The WorkFit consultant has helped improve the way that the employer works with him and is happier in his job.

Parent member

The support and training was very constructive and will help us all to support our employee with Down's syndrome and move forward together.

Local M&S store

What we are doing next

We are keen to expand WorkFit and have successfully secured funding for two new Employment Development Officers who will be working across Wales and the North East/North West of England.

Calling All Local Groups and Employers

As we now expand the programme with the new Employment Development Officers, now more than ever we need your continued support. We are currently looking for inclusive employers based in London, Wales, Devon and the North East of England.

Our current partnerships with local groups have been instrumental in securing us successful placements, disseminating information about the project within their locality to families, employers and also identifying other support organisations we can work with. A big thank you to all the local groups who have been involved.

In addition to the above funders we have also received generous support from The Sylvia Adams Charitable Trust.

For any queries please email dsworkfit@downs-syndrome.org.uk or visit our website www.dsworkfit.org.uk For any queries about how work will affect your benefits please contact our Benefits Advisors on 0333 12 12 300.



Helen Keeler volunteering at Downright Excellent (DEx) in London.

"Helen is uplifting and inspiring. She has reinforced that all our hard work with younger children with Down's syndrome is hugely worthwhile. She is a great role model to our parents and carers who use our service".

DEx Projects Coordinator.



DSActive

The DSActive adult programme has just celebrated its first birthday! Launched in April 2013, the programme, focussing on recruiting people aged 18+ to DSActive football and tennis sessions, has been a huge success and has seen several new players enter the fray.

Originally aiming to launch three football teams and three tennis sessions every year until 2016, DSActive's adult programme has exploded out of the blocks, seeing a massive eight football teams and three tennis sessions launch in just 12 months.

Joining the 18+ football ranks were; QPR Tiger Cubs; Chelsea FC Lions; Inspire Suffolk Mini Tractors (formerly Ipswich Town); Cardiff City DS Bluebirds; Exeter City; Derby County; Stoke City; and Watford FC. Moorside Rangers, Fulham FC Foundation and Newcastle United Foundation are all preparing to launch an 18+ session, and Blackpool FC are soon to make their session an all ages affair.

Added to the 18+ tennis programme this year were; Sutton Tennis Academy; Gosling Sports Park; and Milton Keynes Tennis Club, with DSActive and partnering organisation the Tennis Foundation aiming to launch a number of new sessions over the summer.

DSActive's National Festival will also take place for the fourth year running. This year's festival will take place at the incredible St George's Park in Burton-upon-Trent. Home to the FA, St George's Park (the National Football Centre) plays host to all of England's elite squads but has kindly agreed to open its doors to DSActive on Sunday, 29 June. With over 16 teams expected to take part, this promises to be the biggest and most exciting festival yet. Anyone with Down's syndrome aged five upwards is welcome to take part – please contact DSActive beforehand.

Another exciting development for DSActive is our first 'Coach Ability' project which will see six DSActive players complete the FA Level One Coaching Qualification. The project, which will be the first coaching course created for people with Down's syndrome, will take place throughout June and July, with each player receiving their FA Level One



Coaching Badge. DSActive will then work with our partnering football clubs to secure voluntary and possibly paid roles for each player in a coaching capacity. The project will be filmed from start to finish by production company 'Big Button' and, if successful, will become an annual fixture for players aged 18+ within DSActive.

DSActive has also launched a new website, with areas for both football and tennis. To see our latest news, photos and videos, please visit www.dsactive.org or see our Twitter account (@DSActive), Facebook page (/DSActive) and YouTube channel (/DSActiveUK).

To enquire about your local team or the national festival, or to offer your services as a volunteer, please contact DSActive Sports Manager Scott Pollington Woods at scott.woods@downs-syndrome.org.uk or DSActive Sports Officer Matt Maguire at matt.maguire@downs-syndrome.org.uk.

Using a Smartphone

Dave and Julie Thomas

Like all teenagers, our son Stephen wanted a phone “with apps” just like his friends. As parents of a child with Down’s syndrome, we wanted him to be able to call us if he was lost or needed help and to be able to text us to let us know he was on the right bus from college. We also wanted him to have a device that was easy to use, and not ridiculously expensive in case he lost or damaged it.

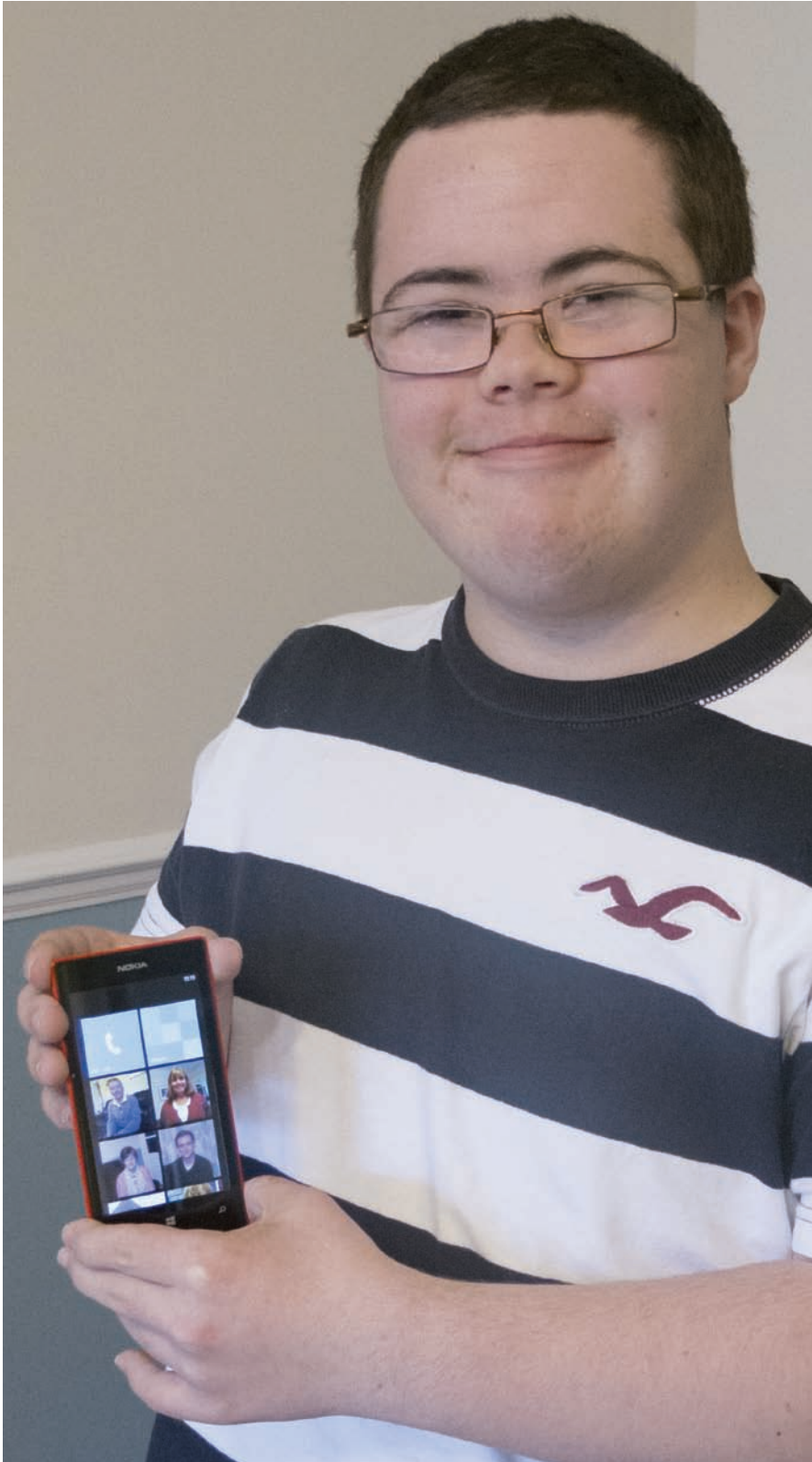
When I started working for Microsoft, I was given a Windows Phone as my work mobile, so I already had some ideas about how we might meet some of these requirements, and we were able to purchase a pay-as-you-go Nokia Lumia 800 for less than £80 (this particular model has now been superseded, and Stephen has recently ‘upgraded’ to a Nokia Lumia 520 for a similar price). I’m sure other Smartphones can also be similarly customised, but this article specifically relates to how we adapted a Windows Phone for our teenage son Stephen to make it as simple as possible for him to use. We had a number of goals:

Although he is fairly good with technology, we were especially concerned that if Stephen were in a ‘panic’ situation, he would not become flustered or confused by the device when he needed to call one of us urgently.

We wanted Stephen to be able to play games and use appropriate apps without becoming confused by too much ‘clutter’ on the screen.

In an emergency, we wanted the ability to be able to locate Stephen’s phone and therefore, hopefully, Stephen himself!

Windows Phones have a ‘tile’ based user interface. Tiles can be ‘pinned’ to the phone’s front screen, can be adjusted to be different sizes, and can also be ‘unpinned’ (i.e. removed) from the front screen. The tiles can also be made to



show information (what Microsoft calls 'Live Tiles') often in the form of words, but also as pictures for some applications.

By default, a Windows phone comes with a variety of applications, represented by these tiles, on the front screen.

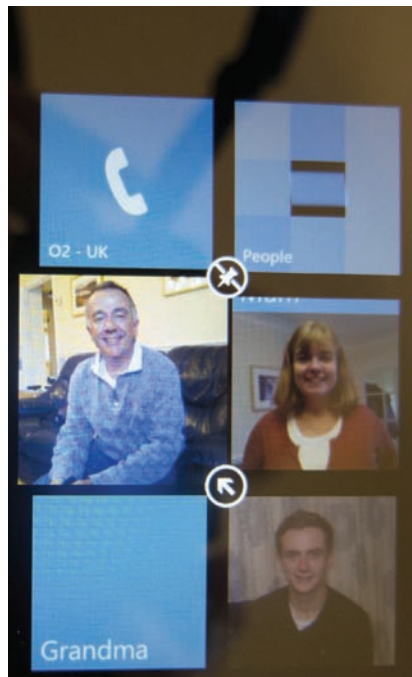


Some of these, such as the Text/SMS tile, would be really useful, others such as Internet Explorer and Email, would be less immediately useful (especially as we had not purchased any data capability for the phone other than Wi-Fi access).

When a tile is pressed for a couple of seconds, it displays two small icons – one to change its size, and the other to 'unpin' it. The first thing we did was to unpin all the unwanted applications from the start screen – this doesn't actually remove them from the device, so it is also really easy to add them back in again later if needed, and they can all be accessed by 'swiping' the screen to the left. It does, however, remove all the 'clutter' from the Start screen making it really simple for Stephen to find the function he is looking for. Selecting the 'large' tile size also made the individual functions really easy to spot and to select.

Next we added important people and phone numbers to the address book along with photographs – mum, dad, brother, grandma and a picture of the house (to differentiate the landline from our mobiles). These were each then pinned to the start screen. Now all Stephen has to do to contact his mum is to tap her on the nose and choose from 'call mobile' or 'text!' (We also added a variety of other friends and relatives and learnt that it was not

such a great idea to add too many people to the address book – on his first day at college, Stephen decided to call each person in his address book in turn to let them know how much he was enjoying it, thus working his way through most of his call credit!)



By default, all the installed games are 'hidden' behind a single 'Games' tile on the front screen so that they can all be accessed really easily but don't clutter things up.

When you set up a Windows Phone for the first time, you also set up a 'Microsoft Account', or link it to an existing one (e.g. a Hotmail account). It is also possible to set up a payment mechanism to allow Apps to be purchased. Not wishing to be faced with a huge credit card bill, we bought a Microsoft Gift Voucher and associated that with Stephen's account – to our surprise however, he has mostly downloaded free games and thus most of the voucher is still unspent.

Even in the middle of a game (or any other App), if Stephen needs to send a text or make a call, all he needs to do is to press the 'Windows' key at the bottom of the phone, and this will always take him back to the Start screen – there are no complex 'exit' processes to remember.

There are a variety of Apps in the Windows Phone Store to allow the location of a phone to be shared with friends and relatives. So far, we haven't used any of these; because we know the username and password of the Microsoft Account associated with Stephen's phone, we are able to visit <http://windowsphone.com> and use

the 'Find My Phone' feature to locate the phone (and hopefully, therefore, it's owner!) Thankfully, thus far we have not needed to use this feature other than to test that it works!

We have been surprised by the ease with which Stephen has managed to send and receive text messages (albeit with some interesting spelling!). We did look at a simple App called 'Lightning Dial' (now renamed 'Shortcuts') that allows Text Messages to be pre-configured (e.g. "I'm on the bus") and associated with a picture so that the user simply clicks on a tile of, say, a bus to send the text message to a particular person. However, we've found that Stephen hasn't needed to use this, and he religiously texts his mum at 16:05 every day as he gets on the college bus to let her know he is safely on the way home.

On the bus, Stephen noticed that many of his friends listened to music on their phones, and he asked if he could do the same, so we have added the music tile to his Start Screen and installed some of his favourite music to enable him to do this as well.

Stephen started off with a 'pay as you go' SIM. Initially, this proved more than sufficient for his needs but as he began to send text messages to his friends, we found that he was quickly reducing his available balance – a cause of some concern as we wanted him to be able to call us in an emergency. We've therefore moved him to a SIM-only monthly tariff which gives him unlimited texts and 300 minutes of free calls for £11 a month – less than he was consuming in text messages! Because he rarely makes calls (after his initial enthusiasm!), he has gone no-where near the 300 minutes, but it makes us feel a lot happier knowing that he will always be able to call us if he needs to.

Although we started this experiment wondering if Stephen would be able to use the technology, we have discovered that being able to simplify the Start screen, and fill it with simple 'visual clues' on the tiles has enabled Stephen to easily access the phone's features, as well as giving us a bit more comfort that if he found himself in an unfamiliar situation, he would hopefully be easily able to get in touch with us. As we said at the outset, some of these customisations/simplifications could probably also be made to other types of phone, but for Stephen this has turned out to be the perfect device to allow him an increased level of independence, and to be just like his friends.

My Son Oliver Hellowell

By Wendy O'Carroll

My name is Oliver



I am 17 years old and it is March 2014



I am a wildlife and landscape photographer



I have Down Syndrome and I have a GREAT life!



I have taken ALL these pictures in the last 3 months



I wonder what amazing pictures I'll take in the next 3 years!



Oliver Hellowell www.oliverhellowell.com
Find me on facebook at: www.facebook.com/OliverHellowellPhotographer

My son Oliver was born in July 1996 and was diagnosed with Down syndrome and significant cardiac problems which required open heart surgery to repair three heart defects at three months old. It was thought he would not even survive to reach surgery. At 18 months old I was told by a physiotherapist that Oliver suffered from severe hypotonia (extremely poor muscle tone) and that although I should encourage some physical activity my son would obviously "never be sporty".

At 2 years old it was noted that Oliver laughed and cried without sound and at 3 years old the speech and language therapy service described him as having verbal dyspraxia in addition to speech

and language delay associated with DS, and stated it was "unlikely" his speech would ever be understood by an unfamiliar listener. At mainstream primary school he was informally excluded on several occasions due to 'impulsive and challenging behaviour' and was formally diagnosed with ADHD at 10 yrs old.

Oliver is a living testament to the fact that life is all about what you CAN do and not what people say you can't do.

I started signing to Oliver at 10 months (always saying the word at the same time) and he started using sign himself at about 18 months old. He knew what

he wanted to say he just couldn't get his mouth into gear yet! He started school at 4 years 2 months, and was able to sign over 350 words. Oliver loved to learn, we made learning fun, and at 4 years knew all his colours and recognised numbers 1 to 10. With home made cards and activities following the "word matching, selecting, naming" strategy promoted by Sue Buckley, he could read 75 words when he started school and now enjoys his library of over 400 books at home. I found outlets for his hyperactivity and channelled it into activities which he could enjoy and benefit from. He loved football, basketball and snooker and was skateboarding by the time he was 9 years old. With patience, optimism and specific targeted activity and encouragement Oliver's speech production blossomed and he is able to hold a conversation with anyone, discuss the merits of everything from a Volkswagen Golf to a Bugatti Veyron with his big sister Anna, and has been interviewed on BBC radio about his photography on several occasions.

Oliver's father left when Oliver was young and has chosen not to see him since he was 6/7 yrs old. Mike O'Carroll, Oliver's stepfather, came into Oliver's life when he was 9/10 years old and Oliver was fascinated by the fact that Mike was a photographer. He wanted to be able to "take pictures like Mike". With Mike's love, patience, guidance and targeted tuition, delivered in small chunks at Oliver's pace, Oliver has been able to extend his knowledge and expertise and develop his own unique style. Oliver can enjoy and utilise the world of photography as both a tool for him to record what he sees in the way he sees it, and also as something which brings him a strong sense of achievement and self esteem.

In June 2013 I set up a face-book page to publicise Oliver's photography and achievements. Oliver's fame spread quickly and in less than 4 weeks he had over 1,800 fans/likes for his 'page' from across the world. Oliver has a large world map on a wall at home and as comments appeared from countries far and wide, Oliver wanted to 'find' the people commenting on his page. Oliver's 'fans' were asked if they would let him know where they came from so that stickers could be placed on the map. Over 1200 responses were received in 48 hours from places as diverse as Zimbabwe, Alaska, Tennessee, Europe, Lebanon, Kuala Lumpur, Peru, India, New Zealand, and the list goes on...

Many were parents of children with DS saying how inspired and encouraged they are, many love to follow and promote a positive story, some are photographers who find his style interesting and some just simply love his photos!

9 months on and Oliver has over 8,000 fans – people across the world all connected and inspired by a young man with DS.

Oliver lives a rich, varied, interesting, life and is NEVER bored. He loves books and magazines. (He has over 250 car, fishing, wildlife and skateboarding magazines.) He enjoys playing snooker on the medium sized snooker table in our conservatory and playing football and basketball outside. He watches endless re-runs of Top Gear on 'Dave' and owns every DVD David Attenborough has ever made! He goes fishing one day every week with Mike, spending some time actually fishing, some time sitting

in his 'bivvy' with his books, magazines and 'Nintendo DS' and will then pick up his camera and go off wandering around the fishery taking photographs and chatting to other fishermen. We frequently pop across to Wales at weekends to find great locations to wander and take pictures, often waterfall hunting or visiting castles as Oliver is fascinated by history.

I find Oliver's photography particularly thought provoking as he so frequently takes pictures of things other people don't see, notice or care about.

Oliver's dream is that one day he might be able to make enough money for us to do a 'road trip across America' in a big Winnebago! He is so keen to see and photograph the birdlife, wildlife and landscapes across the USA.

I believe that the particularly strong message to be taken from 'Oliver's story', is that he is NOT what some would describe as 'high functioning'. One often sees clips/articles/stories about young people with DS playing the violin, becoming Mayor, delivering lectures etc and it becomes evident quite quickly that this is 'a particularly able' person with DS. This often enables parents to 'cop out' and think 'ah yes but my child isn't as able as that, so he/she could never do that.' Oliver was NOT born particularly able. He had, as you have already read, many problems and difficulties which made his path a more difficult and challenging one to tread. But with the right attitude, encouragement, optimism, ENJOYMENT and determination, an enormous amount can be achieved.

In my professional role within Ups and Downs Southwest, the organisation I founded after Oliver's birth, I have had the great privilege to be involved with over 500 children and young people in the last 17 years and they vary ENORMOUSLY. I know of many young people who are 'more able' than my son. Yet Oliver enjoys an interesting

and fulfilling life, is very proud of his ability and achievements, and brings SO much to the lives of those around him. I have a daughter who is 26 and doesn't have any disability but I can assure you that her life has not been without incident and difficulty!

I know of a couple of young people the same age as Oliver, who do not have DS. They have dropped out of college, lost jobs, got in with the wrong crowd, are unkind to their parents, may be taking drugs etc. These sets of parents are worried to death about their sons and how best to help them to find the right path. Meanwhile my son always asks me how my day has been, enjoys my company (and I his!), leaves the lady at the supermarket checkout laughing, and has two little nieces who adore him and beg to visit and spend time with him. He has fans and followers all over the world who enjoy and are inspired and encouraged by his photography and his achievements.

YET when these boys were born – one was seen by society as far less valuable. My son was seen as a burden – the others were seen as cause for celebration. Everyone told me they were sorry.

There is a huge piece of work to be done to change the way we and 'society'

look at Down syndrome, and at what we see. What do we perceive as valuable? It so happens that I can with all honesty put my hand on my heart and say that if I was presented with a magic wand, I would not change my son. Down syndrome is an intrinsic part of who he is and is part of what makes him such a wonderful and amazing person. He has brought such huge value to my life and I am enthralled and inspired by him. His life and his world are incredibly valuable and I can assure you, he enjoys his life far more than your average 17 year old!

My greatest wildest dream, is that one day we might reach a point when people who discover they are expecting a baby with DS, react the same way they would if they were told they were expecting twins or triplets. The reaction would be more of a "Wow! I wasn't expecting THAT! This is going to be a bit different!" Maybe not in my lifetime?

Life with Oliver is all about 'enjoying the madness' as my husband describes it – and although life can be challenging it is certainly never dull! Oliver is a funny, amazing, random guy who brings a smile to our faces several times every single day. He provides his own unique perspective on the world – and we are all the richer for his being here.



www.oliverhellowell.com | www.facebook.com/OliverHellowellPhotographer



Aim for the Moon ... that way you're bound to reach the Stars!

Kim Reuter

Everyone says your first baby will change your life. So I was prepared. No really. I was ready for the sleepless nights, the midnight trips around the 24 hour supermarket, the gone for good waistline, and the cocktail of exhaustion and euphoria.

I was a mature first mum. I was ready for this baby.

The 12 week scan revealed a baby boy was on his way. I admit it was a shuddering shock – boy?! Well that was a new one – we don't do boys in our family and so I clearly remember that first sleepless night I had, not only grieving for the spunky, funky little girl (called Ruby) I had dreamt of, tottering about in baby Doc Martens and purple tutu, but trying to get my head around this BOY thing. But good old Mother Nature did her stuff and it didn't take too long before I had adjusted and decided that all the bits I didn't get about boys I would just leave for his dad to sort out and all would be well.

I was so very curious as to how this growing being inside me (now renamed Ruben) was to turn out, I couldn't wait to meet him and start on life's adventure together.

Having worked in the field of additional needs for a long time, running Shabang! theatre group which specialised in making shows for special education settings, I felt very secure in the fact that it would be far too much of a coincidence if I was to have a baby with "special needs" myself. A bit like lightning striking twice. It didn't stop me from asking the nurse who had done my scan, if she'd noticed anything different about the thickness of the baby's neck though. She hadn't, so I didn't think much more about the possibility.

I did have a memorable dream one night about having a child with Down syndrome and him being in a school drama production and being a really good actor and me being in the audience feeling dead proud. But of course pregnancy brings all kinds of extraordinary dreams and I thought little of it.

I worked all through my pregnancy, doing shows in schools, sorting the house out a bit and awaiting the arrival of my son Ruben.

When he was born (3 weeks early) I remember through my Pethidine haze taking my first look at him, before the cord was even cut, turning to his Dad and saying "We have ourselves a baby with Down syndrome." He of course thought I was being dramatic ... the effects of the drugs and all that. I watched the doctor, midwife and nurses whisk Ruben away. I knew what they were thinking, I knew what they were whispering, I knew what they were about to tell us, but by then it was too late – I had already fallen in love. So this was who Ruben was – a beautiful little boy with an extra chromosome – I think I probably loved him even more.

In the very early days I resisted Googling "Down syndrome" – I just wanted to get on and enjoy this exquisite little creature who truly was busily changing my life forever.

It was probably the well intentioned speech therapist who visited when Ruben was six weeks old and told me his language would "plateau" bla bla bla ... and he would never bla bla bla and not to expect him to bla bla bla etc " that my belligerent pragmatic side kicked in and I read all the research I could get my hands on. I went on all the courses run by all the experts. I was an overnight authority in Down syndrome and I was going to teach that boy of mine to walk, talk, read, write and excel everyone's expectations.

Ruben wasn't the brightest spark in the fire at his child development group so I realised I had a lot of work to do. The language development milestones that his peers were reaching, seemed a bit trickier for him.

My researching days (actually mostly nights) led me to explore the world of neurological enhancement through movement and the theories made a lot of sense to me. I started to do left brain

/right brain. coordination, cross lateral exercises with him and could see that they were helping. I introduced him to an amazing American reading technique called Love and Learning which taught whole word reading and Ruben quickly made progress – yes he was definitely a visual learner! And a little and often approach seemed to suit.

As I waved him off for his first day of school I breathed a sigh of relief thinking someone else was now taking on the baton of teaching my son. It didn't take long before I realised I still needed to carry on with all the activities I was doing at home. I learnt to aim high, then readjust and set new sights. I gave lots of input to the school – bringing in visual resources, buying them a digital camera for them to keep a visual diary, making a beautiful conversation diary for Ruben to take in every week, compiling behaviour sticker charts for them to work to so we could have consistency with home, providing Numicon kits, teaching them Makaton signs for songs and assemblies. Crikey it was hard work, but worth it. The more you put in the more you get out.

A fabulous Lottery grant now allows Shabang! to run preschool sessions for children with additional needs and courses in neurological intervention for parents where we can pass on the things Ruben has taught us.

At five Ruben started swimming lessons with an inspirational teacher, Gemma who trains the GB Down Syndrome Squad. He trains with her still and is now the youngest in the squad. He has competed and won medals in the Down Syndrome European and National Championships and the Special Olympics Summer Games. His swimming inspired a documentary story line for the CBBC series "My Life", made by Markthree Media, resulting in a short film called "Breaking Free". It featured Ruben and two other fantastic youngsters with Down syndrome and was nominated for a Children's BAFTA.

Meanwhile Ruben has grown up alongside Shabang! He joins in with shows, signs Makaton to our short films on You Tube and even stars as Scupper the Cabin boy in our Makaton DVD. His forays with CBBC led to two reports for News Round on disability. He is in mainstream high school and at 14 has just completed his BTEC in Performing Arts.

Children with Down syndrome display a range of abilities, just like the regularly put together population – but I am a firm believer that quality early and continuing intervention can make an enormous impact on the achievements of our

children. Appropriate teaching techniques which play to our childrens strengths, make a tremendous difference to what our children learn and achieve. I see our children as little beacons of hope. Role models for younger generations and persuasive tools to expectant parents who may worry about what life with a child with Down syndrome might bring.

As proud as I am of all of Ruben's achievements, I am most proud of his sweet nature, his determination, his love of the world and his ability to hopefully change a few attitudes and perceptions along the way.

My time as his mum has been the most rewarding, exciting, loving, happy, positive journey that I could ever have dreamed of. I thank my lucky stars I had a baby with Down Syndrome. That he was a boy. That he was Ruben. That he was mine.

As he matures into a young man all I can say is *Watch out world ... Here comes Ruben!*

Kim Reuter is Co-Founder of Shabang Inclusive Learning and happy mum.
www.shabang.org.uk

Esmee

Kate Chadwick

"I can't quite see the neck, baby's moving around too much. I'm just going to get the sonographer to have a look".



Those were the words spoken by the scanning midwife at our 12 week scan which struck dread into my heart. I had felt from a very early stage that something was not right with the pregnancy, no particular reason, just a hunch I had. As she left the room I grabbed my husband Jon's hand and told him something was really wrong. He had reassured me previously when I told him I was worried about this baby but now he looked just as terrified as I felt. Our daughter Isabel, whom we had taken along due to a lack of child care, and who had been very noisy and fidgety after waiting a long time, suddenly went silent and crept along the floor to slip her tiny hand in between ours.

The sonographer spent a while looking around, taking measurements then told us that the nuchal translucency (NT) test was showing abnormalities and that we would be taken through to talk to a screening midwife. From that point onwards it was as if I was looking down on someone else receiving this news. It couldn't possibly be us. We walked across the waiting room we had been sat in so excitedly just a few minutes before and I gazed at the other couples, some eagerly expectant, others looking at the pictures of their little ones, and it all felt so unreal. In the side room we spoke to a screening midwife and a consultant who told us very frankly, though not unkindly, that whilst our baby's nuchal fold measurement was within the normal range (just) the fluid extended all the way down her spine. In their opinion this meant one of two things; that our baby had a chromosomal abnormality, most

likely Turner's syndrome or possibly Down's syndrome, or a major structural defect. They mentioned cystic hygroma, Patau's and Edward's syndromes although they thought these less likely. There was so much uncertainty. I felt numb, hopeless.

After much Internet searching and endless hours of talking I suddenly thought of what else we had seen that day; our beautiful baby wriggling around, full of life. At that moment I knew for certain that, despite the terror I felt, termination was not an option for me. Jon, however, was struggling with an inner turmoil worrying about the impact this could have on the family life we already had. For this reason we felt we needed to know what to expect hence, after much deliberation, we opted for CVS.

At this point the ultrasound scan showed the fluid all down our baby's spine had completely resolved and the NT measurement was well within normal limits. The consultant told us he thought that the most likely scenario was that the baby had a minor heart problem such as a ventricular septal defect (as I had one of these from birth and it can be an inherited condition) and nothing else. We left feeling reassured and hoping and praying he was right. He was not.

I received a phone call from the screening midwife a few days later. She asked me where I was and who I was with and I just knew. I didn't need her to say the words "I'm afraid it is Down's syndrome". We had decided that if this was the outcome we wanted to know what sex the baby was; "A little girl".

Despite feeling I was prepared for this news I felt devastated. I spent the next few days with my husband trying to work out why this had happened to us, what our future lives would be like, what if I didn't feel any connection to this baby when I saw her and lamenting the fact that Isabel would lose out on all the things sisters usually do together.

Despite reading others' positive stories of life with their child with Down's syndrome I still worried continually for our family. And in fact I needed to do this as part of the grieving process for the child I had been expecting and wasn't going to have, but I had begun to feel our little girl kicking and wriggling around and I already felt so protective over her. Despite both Jon and I feeling now that we wouldn't be able to abort our baby we were advised to consider both options. We did this and it was very cathartic and helped us confirm our decision not to terminate. Almost everyone we told reacted with such positivity and we felt so supported.

From that point onwards we attended a great many scans and hospital appointments. We were under no illusions about our daughter's possible myriad of health conditions but at every scan we were told that no major issues were found (with the proviso that nothing was certain at this stage, therefore allowing us no possibility of becoming too excited and hopeful for the future). But as the pregnancy progressed smoothly we did begin to get excited about our new baby's arrival and we couldn't wait to meet her.

Despite it being so distressing we feel very lucky now to have had the time during pregnancy to come to terms with our daughter's diagnosis. We had told Isabel her little sister had a condition which meant she might need more help in doing some things and in learning new things. Isabel was determined to be the one to teach her and proudly (and loudly!) informed everyone she met that her sister would have Down's syndrome! She stunned several checkout assistants into an awkward silence whilst they shot me a sympathy smile, so I would agree with Isabel and just say how much we were looking forward to her being here.

At 37 weeks exactly, after a trouble free labour in the birthing pool and natural delivery I gave birth to Esmee Annie weighing a fantastic 7lb 5oz. Thank goodness she didn't stay in another 3 weeks!

As she was placed on my tummy I was overwhelmed with an intense love for her and gazed at our beautiful daughter in adoration. She looked just like Isabel when she was born. Esmee breastfed almost straight away and we never really had any problems with it thanks in part to our amazing infant feeding co-ordinator. Esmee breastfed exclusively until after her 2nd birthday and never once dropped below the 50th centile on the Down's syndrome growth charts.

Her early weeks were difficult as she picked up Influenza A at 6 weeks old. I had been taking her to the doctors for weeks and each time I was turned away. Then Esmee stopped breathing and turned blue in the doctor's office and we were sent straight to Birmingham Children's Hospital A&E where Esmee was admitted to the High Dependency Unit. This was a desperately worrying time and she was so poorly that we did think at one point we could be leaving the hospital without her.

Esmee had other hospital admissions at 8 weeks and 14 months for bronchiolitis and developed chronic constipation but otherwise she has had remarkably good health. She didn't have a heart defect, her hearing is so far normal but she

does need glasses and needs her tonsils and adenoids removing to deal with her sleep apnoea.

Having Esmee (now 2 years 5 months) has brought so much joy into our lives and that of everyone around her. She has a wicked sense of humour, adores her big sister, who in turn dotes on her and goes out of her way to make her happy, and enjoys life to the full every day.

We are lucky that her speech is coming along extremely well so we have avoided some of the tantrums associated with not being able to make herself understood but she doesn't walk yet so she can sometimes get cross that she can't run around with Isabel. She is sociable and loves playing with her sister or friends at nursery which she attends 2 mornings a week and where they use Makaton with all the children. She is stubborn, excitable, friendly, sometimes grumpy, inquisitive, cheeky and so much more. Just like any other child.

Jon and I couldn't imagine what our lives would be like when we first got Esmee's diagnosis but we needn't have worried as our lives are infinitely better for having Esmee in them. Our girls show us every day that we should be thankful for our wonderful family, each of us different in our own ways. We look to the future with positivity and hope. I do worry of course, for example about Esmee being bullied, but I also worry about Isabel being bullied. Granted, Esmee may be more prone to bullying, but as she currently doesn't put up with anything she's not happy with we have to hope that continues as she grows older. We feel immensely blessed to have two such amazing girls in our lives, one of which happens to have Down's syndrome.



Gross Motor Skills for Children with Down Syndrome

A Guide for Parents and Professionals

By Patricia C. Winders PT. (Second Edition). Woodbine House. 2014.

Review by Jane West



When a friend asked me to review this book, I felt it would be interesting to do so. I have worked in Paediatric Physiotherapy for 20 plus years and have experience predominantly in

Special School and Child Development Centre work. My caseload has included children with Down's syndrome but I have, I admit, felt that these children would naturally progress with their gross motor skills, all be it at a slower rate. Therefore the experience of reading Patricia Winders' book has been enlightening and made me think in more depth about my own clinical practice.

Patricia's book has an informative introduction where she explains, very clearly, the key factors and time scales around physical development. She focuses on, physical factors (hypotonia, hypermobility, decreased muscle strength, short arms and legs and medical problems), learning styles and behaviours that a child with Down's syndrome may use and the need for time to consolidate skills. The introduction also lays out clearly the structure of the book and critical times for intervention.

The main body of the book is divided into the pre-walking skills leading up to independent walking, post walking skills and finally posture and lifelong physical management. In these sections there is a wealth of detailed activities with great pictures to accompany them. I particularly

liked the fact that for each activity there was a section on the compensatory movement patterns (tendencies) that a child may use rather than the desired movements. This would be useful to parents and professionals alike. The milestone checklist at the end of a set of activities was again very detailed and may cause some parents a level of anxiety if their child was struggling to meet these milestones, although no timescale is given.

I was particularly interested in the section on foot management and felt that it was written extremely well with good use of pictures and explanations. It gave sensible advice without being prescriptive leaving the child's own therapist room for discussion re suitable footwear at the correct point in the child's development.

In the final part of the book there is useful advice re correct posture and the warning signs of Atlantoaxial Instability. There is also an equation to calculate maximal heart rate and from the target heart rate for cardiovascular exercise, as well as general advice for helping your child to be successful in their chosen physical activity.

The appendix consists of various worksheets which I personally found confusing. I am not sure that many professionals would use them and they are not "electronic record friendly." Parents may find them helpful but they have a lot of information, activities and motor checklists to get through before reaching this point.

This is very much an American book and therefore the use of language can be confusing, Patricia refers to "diapers" as opposed to nappies for example. More confusing is the use of technical terminology, creeping and crawling are described in the opposite way to our English understanding and bridging does not appear to involve the child's bottom coming off the floor. The book does have highlighted boxes to explain technical terminology with descriptions which would be useful for parents.

Any website links are for American companies which may not particularly helpful to a British readership.

So would I recommend this book? In short yes I would. It has a wealth of ideas for physical development and it is obviously the author's passion. If I was recommending it to a parent I would warn them about the different vocabulary and that it would be more helpful as a reference/ideas book rather than a cover to cover read. It is probably not a "first read" book following diagnosis as there is so much information and may be quite daunting for new parents.

Professionals, I feel, would find the book useful again for reference/ideas. As I said at the beginning it has made me think differently about this group of children and role of physiotherapy input. I can see where the author is coming from when she writes, and I paraphrase....

"Physical therapy services are critical to develop the essential movement components and postural foundation to build a body that is fit and functional throughout life"

The book certainly provides the information for a parent and a professional to do this.

Jane West has worked in Paediatrics Services in the NHS for 18 years. For the past two and a half years she has worked for a local charity as well as developing a private paediatric physiotherapy practice. www.janewest.co.uk

I Love You Natty

By Mia and Hayley Goleniowska



This is a sibling support book aimed at young children. It is available to buy from Amazon for £5.99. Hayley Goleniowska is a parent member

and blogger at Downs Side Up.

Review by Kate Powell,
Editor of Down2Earth Magazine

I really like this book because I am impressed, it's great.

This book is about a sister (Mia) writing about her sister (Natty) with Down's syndrome and they like spending time together. This book is worth reading because it's educational for lots of children of all ages. This book can help a lot of people's views towards people with Down's syndrome. This book can be the start of friendship between siblings. I will give

this special book 99 stars. It's very new. Please read this book – don't look away.

I have included a link to Mia's Mum's Blog: <http://www.downssideup.com/>



The Essential Guide to Health Care for Adults with Down Syndrome

A Guide for Parents and Professionals

By Vee Prasher and Anisha Prasher. Second Edition. BILD Publications. 2014.

Review by Dr Salim J Razak



This second edition discusses various health issues faced by people with Down syndrome. It is a concise and comprehensive guide looking at a range of different issues including medical issues such

as vision, hearing, heart and circulation, sexual health and psychological, emotional and mental health issues. It is written in a very readable fashion making it an invaluable resource for both specialist and non-specialist healthcare professionals, as well as carers of people with Down's syndrome.

The book starts off by discussing some broad personal and social issues faced

by people with Down's syndrome before looking at more specific health issues. It also contains some very useful appendices including checklists to be used for health checks and range of further resources including sources of information and contact details of various support agencies.

I found the book clear and easy to follow and full of useful information relevant to the specific health challenges faced by people with Down syndrome, and I am hopeful that it will help healthcare professionals to better understand some of these often complex and intertwined health difficulties and contribute to the improved healthcare of people with Down syndrome.

Dr Salim J Razak is a Consultant in the Psychiatry of Intellectual Disability.

KILLA

By Kevin Kilbane

Review by Paul Zanon



When Kevin Kilbane contacted the Down's Syndrome Association in 2005 he was in need of a great deal of information and support regarding something he had little knowledge

of – being a parent of a daughter with Down's syndrome. Within literally a few weeks of his first interactions with the DSA he agreed to become a patron and

has ever since become an incredible supporter of the DSA on a number of fronts, including fundraising, numerous public appearances at DSA events throughout the UK and is also now a patron for the DSAActive programme (sports for people with Down's syndrome).

In 2013, Kevin raised the bar to another level of support. Apart from running the London Marathon for the DSA raising a sterling fundraising total, he also launched his autobiography KILLA (available on Amazon and all good book shops!). The book was ghost written by acclaimed author and DSA parent member Andy Merriman, and is a great story about a very endearing man who also happens to be Ireland's third most capped player of all time, with 110 appearances for his country, including

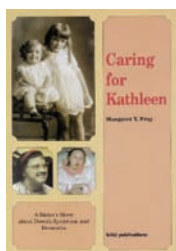
an incredible 66 consecutive matches. Kevin's presence on UK soil wasn't bad either, playing alongside the likes of Wayne Rooney at Everton and also donning the studs for a number of other clubs such as West Bromwich Albion, Wigan and Hull before retiring in 2012.

The book takes you through Kevin's journey as a child of Irish immigrants growing up in a tough region in Lancashire, through his entire football career and his emotions of becoming a parent of a child with Down's syndrome. Some roller coaster episodes which will give you a platform to share empathy and pride.

The royalties of the book are split evenly between the DSA and DS Ireland, so please jump online or go to your local bookshop and purchase a copy!

Obituary of Peggy Fray

By Carol Boys, Chief Executive of the Down's Syndrome Association



It is with deep sadness that I have to tell you about the death of Margaret (Peggy) Fray, Trustee of the DSA.

I first met Peggy in the 1990's when my son Alex was very young. I can

still remember now just how movingly she spoke about her sister Kathleen. The launch of her book in 2000 – Caring for Kathleen – A Sister's Story about

Down's Syndrome and Dementia showed us all the true depth of Peggy's devotion to a sister that she cared for until she died in hospital at age 70 suffering from dementia.

Peggy became a Trustee of the DSA in 2002 and since then we have all been inspired by her gentle, kind and common sense approach to the issues that affect people with DS. Peggy's lifelong mission was that people with DS and dementia should have automatic access to specialist care from professionals with a true understanding of their needs. She often

talked about the importance of dignity and respect – some of the words used by John Langdon Down himself.

We never really did know how old Peggy was but I can remember her telling me about her engagement to a fighter pilot who was killed in World War Two – it isn't that difficult to do the maths!

Despite her great age and increasing frailty, Peggy continued to fulfil her role as a Trustee of the DSA, she would look forward to the journey from St Annes in Lancashire to London and she always stayed at the RAF Club having served in the WAAF herself in the 1940's.

Peggy's death is a huge loss to the wider community of people with Down's syndrome and their families and she will be greatly missed by all of us at the DSA.



www.dsactive.org

WORKFiT

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www.dsworkfit.org.uk



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www.langdondownmuseum.org.uk
www.facebook.com/LangdonDownMuseum



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
Medical Interest
Group

www.dsmig.org.uk



A Registered Charity
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Founder

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Fiona Phillips
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Professor O. Conor Ward

Officers

Chair	Georgie Hill
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
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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.