

journal



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Letter from the Chief Executive



Carol Boys

The cover of this issue of The Journal is a beautiful reminder of this year's Awareness Week.

Lucia looks wonderful in her [#LotsOfSocks](#). Thanks to you, as well as a growing section of the wider community, we sold around 12,000 pairs of socks this year.

In schools and work places across the country people were celebrating and raising awareness. Thank you to everyone who got involved.

The theme of the week was 'Leave No One Behind'. While there have been significant improvements in the health care given to people who have Down's syndrome, we are still concerned that, when it comes to health and well-being, some people are being left behind. You can read more about our Health Alert! Campaign later on in this issue.

Our work on this issue is multi-faceted ... campaigning, raising awareness, providing information and supporting families when they are in need.

This autumn we are rolling out a new training programme for people working in the health and social care sectors which we hope will be part of the NHS's roll out of compulsory training for the sector.

Our DSAActive team have recently launched the [Health Swap App!](#) This free tool is designed specifically for people with Down's syndrome to use on mobiles and tablets. It encourages healthy food choices and getting active with a range of delicious and nutritious recipes as well as ways of celebrating achievements. The DSAActive team will be running nutrition app roadshows around the country during the rest of 2019 talking about the App ... check out the DSAActive website for more details.

In 2020, the Down's Syndrome Association will be 50! We will be celebrating the amazing strides that have been made since the charity began in 1970.

The DSA and its supporters have been at the forefront of the changes in attitude towards people with Down's syndrome and it's very easy to forget just how many changes there have been – acceptance in society, inclusive education, access to major surgery, employment and so many more.

We hope that you will join in our celebrations!

Information for Contributors

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

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

Our document *Information for Contributors* gives full details on submitting an article. If submitting photographs you will also need to complete a DSA photo and film permission form. See www.downs-syndrome.org.uk/about-us/dsa-journal/

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

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 all copyright clearance for any third party material/references/images included; if using references please use the Harvard system; photocopying single copies of articles contained in this journal for the purpose of private use is permissible; for multiple copies and reproduction, permission must be sought from the DSA/author(s); copyright is retained by the author(s); if authors use the same material in subsequent publications, acknowledgement should be given to this journal.

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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: Lucia wearing Lots of Socks during Awareness Week 2019, see page 10.

News

The Shifting Perspectives Podcast launched

Hosted by photographer Richard Bailey, the Shifting Perspectives podcast will tell the stories of people who have Down's syndrome as well as of their families and carers: raising a smile, providing insights and challenging commonly held attitudes and prejudices.

In the first series you can hear Richard chatting with three

amazing young women with Down's syndrome: actor and campaigner Sarah Gordy; his daughter Billie-Jo Strummer-Bailey; and Sarah Merriman. He also talks Dad-to-Dad with Ian Richardson and with social entrepreneur Jane Chong. We're hoping to create more series throughout the year.



You can listen to all the episodes on our website at www.downs-syndrome.org.uk/ShiftingPerspectivesPodcast and they're also available on Apple Podcasts, Google Podcasts and Spotify.

Consultation responses

We've spent a lot of the last six months focused on our submissions in response to important Government consultations that are relevant to the lives of people with Down's syndrome and their family and carers.

These are not the only opportunities we take to work with relevant Government departments, but they do provide a timely opportunity for us to convey what we see are the important issues affecting the people we seek to represent.

We have submitted responses to:

- The Department of Health and Social Care consultation on mandatory learning disability training for health and care professionals. Read more about this in the article on our Health Alert! Campaign
- NICE guidance on dementia
- Mental Capacity Act amendments
- Older people with a learning disability
- NHS 10-year Plan
- Antenatal care for uncomplicated pregnancies
- Public Health England information about Down's syndrome for pregnant women (ongoing)
- Antenatal Screening Wales information about Down's syndrome and Non-Invasive Prenatal Screening (ongoing)
- NHS.Net public facing information about Down's syndrome
- Wales Education Code of Practice
- Nursing and Midwifery Council on the Future Midwife
- NICE Draft guideline on termination of pregnancy

Day to Day support for adults – new social care resources on our website

Early in 2019 we updated all the information on our website about day to day support for adults with Down's syndrome. It includes guidance, information and advice about social care assessments, housing, support, cuts and complaints.

You can find it all at www.downs-syndrome.org.uk/Support-for-Adults. Don't forget, if you have more detailed questions, you can always give our Helpline a call on 0333 1212 300 (Monday to Friday, 10am-4pm) or send an email to info@downs-syndrome.org.uk



Concerns about people with Down's syndrome accessing the justice system

A number of families have contacted the DSA to highlight situations involving the justice system whereby their family member with Down's syndrome has been called upon to provide evidence.

Everyone with Down's syndrome who comes into contact with the justice system should be considered a Vulnerable Witness.

There are clear procedures that must be followed if someone is a Vulnerable Witness; the procedures are referred to as Special Measures. The guidance published by the

Ministry of Justice is "Achieving Best Evidence in Criminal Proceedings: Guidance on interviewing victims and witnesses, and guidance on using special measures".

We are concerned that a common experience among these families is that of the person with Down's syndrome not being considered a reliable witness. We would like to emphasise that each case should be treated individually and on its own merits avoiding any preconceived assumptions about people with Down's syndrome and their capacity as witnesses.

We will monitor the situation and provide support and information to families who contact us for advice. We continue to strive for equality of access to all areas of society for people with Down's syndrome.



Shauna's story grabs the nation's attention

When Shauna was 9 year's old, her teachers told her Mum, Margaret, that her daughter was a "health and safety risk" and that she wouldn't be allowed to learn to swim like the rest of her class.

17 years later, Shauna has represented Great Britain in the Special Olympics team, is the 'face' of the 2021 Special Olympic Summer Games in Liverpool and works at a local café.

Margaret shared Shauna's story with us and we shared it just before Awareness Week. Shauna's story really grabbed the nation's attention and she was featured on her local BBC news, in The Sun and got a mention on Zoe Ball's Radio 2 Breakfast Show!

You can read about Shauna's journey at www.downs-syndrome.org.uk/Shaunas-story

Having A Voice

The Having A Voice groups have had a busy six months, helping us create new resources and influencing our campaigns and policy.

In the run up to Awareness Week the members fed into our ideas around the theme of [#LeaveNoOneBehind](https://twitter.com/LeaveNoOneBehind)

and also contributed to the development of the resources for schools that we published. They are also playing an important part in the development of new resources on emotional well-being, discussing what makes them happy, relaxed and how they can support their friends.



How we communicate with you...what do you think?

The DSA communicates with its members and supporters in various different ways. We've created a short survey so we can find out what you think of what we are doing at the moment

and how we are doing it.

Please go to www.downs-syndrome.org.uk/communications2019 to find out more or call 0333 1212 300 to request a hard copy of the survey.

Benefits

Universal Credit and Students

In order to be awarded Universal credit (UC), a student must be entitled to Disability Living Allowance or Personal Independence Payment and also have limited capability for work. They would therefore need to satisfy the work capability assessment (WCA).

Universal credit is means tested so if they have savings between £6,000 and £16,000 it will affect the amount of UC received.

The issue

Previously for those claiming income related ESA, the fact that the student was in receipt of DLA or PIP was generally enough to treat them as having limited capability for work once they had provided a medical certificate.

This provision does not exist within Universal credit which means that students are being refused because they initially do not have limited capability for work.

A possible solution

Apply for contributory 'new style' ESA. A claim can be made even if the national insurance contributions are not met and the student can have their limited capability for work assessed through a work capability assessment.

You should explain that as a full-time student they are not entitled to any benefits and want to make a credits only claim to be credited with class 1 national insurance contributions so this can be counted for their state retirement pension. Although not receiving money, they would go through the motions of making a claim and complying with the other conditions of entitlement, such as sending in medical certificates.

Once they have been assessed as having limited capability for work, they can then proceed to claim Universal credit. Being assessed as having limited

capability for work for ESA allows you to have a limited capability for work for a UC claim.

Some of our members have been informed that new style ESA does not exist and that a claim for Universal credit must be made, this is incorrect. Have a look on the government website for up to date information and telephone numbers for a form to be sent out.

Ask for UC claim not to be decided until the work capability assessment has been carried out.

If DWP refuses the UC claim because the student does not have limited capability for work when they claim, they should stockpile these claims until the student has had their limited capability for work assessed.

For benefits information see our website: www.downs-syndrome.org.uk/for-families-and-carers/benefits-and-financial-help/



Training and Assessment News

The Information and Training Team have been clocking up the miles travelling to all four corners of the country over the last couple of months, delivering training sessions on a diverse range of topics.

Over the last few months, we have held a large number of Tell it Right accredited training days for maternity and antenatal professionals in locations including Harrogate, Sheffield, Wales and Northampton.

There have been education and development events in London, Cardiff, Swansea, Cornwall, Wrexham, Swindon and Liverpool and our relatively new *supporting behaviour, puberty and adolescence* training is proving to be popular, with sessions being delivered in conjunction with a number of support groups across England and Wales.

In addition to these face-to-face sessions, we continue to develop our offering of on-line training with sessions for a number of school settings including secondary schools in Birmingham, London and the South East.

Our supporting adults and health and ageing sessions continue to be well received with these being provided for services in Swindon, Liverpool, Pembrokeshire, Newcastle and Devon in recent weeks.

Our new Down's syndrome awareness and health inequalities training for health and social care practitioners will commence later this year and run throughout 2020.

To complement our training activity, please remember that our specialist advisors are able to provide bespoke assessments for children and adults with Down's syndrome. Our speech and language therapy advisory service is being well used and has included providing assessments in Northern Ireland. Our scheduled courses (at The Langdon Down Centre) on early development, primary education and supporting behaviour have been well supported and new dates added to

the schedule for the remainder of the year.

In the early summer, we held another in our series of information days for families of children and adults with Down's syndrome and more complex needs. Families continue to value these opportunities to meet together and hear expert speakers on a range of relevant topics.

Up-to-date information about all of our training services, our scheduled courses and details of how to access our assessment services are available on our website. Contact us at training@downs-syndrome.org.uk to arrange training in your local area.

Scheduled courses

Early Development: Birth to 4 years

Workshop with information on how to support infant development through interaction and play, with a focus on meeting individual needs. Sessions include how to support communication, language and speech, social development and cognition and how to teach reading and number skills.

9.30 am – 3pm | 24 September 2019
9:30 am – 3pm | 21 January 2019

Social development and behaviour, for children age 3 to 11 years

Study day outlining how to support social development and positive behaviour from early childhood to the end of primary school with practical advice on how to support friendships, play and social skills, and how to support positive behaviour using learning strengths.

9.30am – 3pm | 15 October 2019
9.30am – 3pm | 3 March 2020

Early years and Primary Education, for learners age 4 to 11 years

Study day on how to support learning and development in the early and primary years. Includes advice and practical strategies for supporting learning that draws on the specific learning strengths associated with having Down's syndrome but emphasises individual differences.

9.30am – 4pm | 26 September 2019
9.30am – 4pm | 28 January 2020

Supporting Behaviour from 11-18 including Puberty and Adolescence

This workshop covers how to talk about physical and emotional changes, relationships, sex education, support for social development, friendships, self-esteem and behaviour.

9.30am – 3pm | 29 November 2019
9.30am – 3pm | 10 March 2020

Course venue in Teddington: Down's Syndrome Association, Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex TW11 9PS.

Cost per course: Parent member: £45 | Parent non-member: £70 | Professional: £120

You can find more information about the courses here: www.downs-syndrome.org.uk/Training

Our Training and Information team can also offer bespoke training for schools, support providers and local groups on these and many other topics, including Down's syndrome awareness, support for adults, ageing and dementia.

Please contact the Training Administrator (training@downs-syndrome.org.uk) to find out more.

Health Alert campaign

For a long while now we have been concerned about the variability in quality of healthcare that individuals with Down's syndrome receive and by the health inequalities they experience. This is simply unacceptable and something that we strive to change.



In the last issue of The Journal you will have noticed an insert asking for people's experiences of the health care system. While there have been many positive developments (greater awareness, a duty to make reasonable adjustments) we are very concerned by the number of preventable and premature deaths of people with Down's syndrome.

The circumstances surrounding the death of Joe Ulleri, revealed during the course of the inquest into his death in the spring, were (at the time of writing) the latest shocking example to make the national press. We are working with Mencap and Joe's family to highlight these issues and to campaign for real, meaningful change.

For the last couple of years any death of an individual with a learning disability should be referred to the Government initiated Learning Disability Mortality Review (LeDeR programme). Sadly, this

has shown that, compared with the general population, the median age of death for someone with a learning disability is 23 years younger for men and 29 years younger for women and often for entirely avoidable reasons. Reviews that have so far been published have shown that mistakes in health and social care provisions have been made. We must learn from these occurrences quickly and translate that learning into effective remedial action, which prevents any repetition.

In the first half of the year, the Department of Health and Social Care held a consultation on mandatory learning disability training for health and care professionals. In our consultation response, we said that the proposal to introduce mandatory learning disability training for health and social care staff is a welcome development, but is only one, small, part of the action required to address the unacceptable health inequalities experienced by people

with a learning disability.

Other actions also required include:

1. Increasing the powers of the LeDeR programme, so that their recommendations can be enforced by law
2. Strengthening pre-qualification learning disability training for relevant health and social care professionals
3. Where failings in the quality of care are found, especially in the case of avoidable deaths, criminal proceedings should result in the prosecution of the individuals and agencies involved. This must include charges of manslaughter on an individual or corporate basis, where the failings are serious enough to meet the criteria to bring this level of prosecution.

The Down's Syndrome Association is strongly in favour of all relevant agencies adopting a social model of disability. However, there are some instances where close attention to the specific medical needs of people with Down's syndrome is warranted.

Our response to this consultation is one such instance.

We know that individuals with Down's syndrome have a predisposition to higher incidence of some health conditions. All of these conditions require careful assessment, management and monitoring and where any of these provisions are lacking, the outcome for individuals can be significantly detrimental and in some cases, fatal.

Thank you to those members who responded to our call to share their experiences of accessing health care

(good or bad) in our Health Alert campaign. We were able to include more than 30 case studies in our response to this Department of Health and Care consultation.

We are still seeking additional reports of concerns you have regarding health care, which you can submit via email to info@downs-syndrome.org.uk or by calling our Helpline and telling your story to one of our Information Officers on 0333 1212 300.

Some anonymised quotes we used included:

"Found hospital staff very abrupt/unsympathetic at times".

"GPs at the surgery are also not always approachable – we feel rather "bawled off" at times".

"I have no doubt that once I am no longer around to provide and co-ordinate all my son's health needs, he will not be able to access the care he needs and will undoubtedly have his life shortened as a result".

"The doctor left the room to get a form signed. When she came back she said, "It's no good, we don't do it for people like him".

"The ward staff hardly saw him at all, even though he had a special wrist band with butterflies that said he needed extra help. He was in a single room and after the op they never came near him. I had stayed with him but they didn't check if we were OK at all".

Find out more at www.downs-syndrome.org.uk/Health-Alert/

Pulmonary Emboli and Down's Syndrome

While there are many health implications of Down's syndrome, pulmonary embolism (clots in the lung) has not been regarded as one of these.

In one county of England three deaths from pulmonary embolism have been reported in individuals with Down's syndrome over two years. Many more may have been missed.

We wish to highlight these cases with a view to raise awareness of the potential devastating effects of pulmonary embolism.

We also want to ask you to contact the DSA with any other examples so that we can begin to understand whether this is a major undiagnosed cause of death in people with Down's syndrome.

Case 1: A young woman in her early twenties on the oral contraceptive pill (a risk factor for clots) was seen in Autumn 2016 with a painful swollen leg. A clot in the leg was considered unlikely and no further investigations performed.

In Spring 2017 she was seen with chest pain after a visit to the gym. Muscular pain was diagnosed. She died 24 hours later of a massive pulmonary embolism. She had Down's syndrome and autism, so a clear story of how events occurred differed between the doctors seeing her and her carer's recollections.

Case 2: A woman with Down's syndrome in her early forties had confirmed clots in the deep veins of the legs in her early twenties; this cleared the following year but recurred a year later and life-long anticoagulation was recommended.

Twenty years later she was admitted to hospital with constipation. The admitting team could not understand why she was on Warfarin and noted that she was having falls over the past few months (the team thought

there might be a risk to continuing blood thinners). They decided to stop her warfarin without confirming her background history with her family or in her hospital notes. She died 5 months later of a massive pulmonary embolism.

Case 3: A man in his early fifties with Down's syndrome, dementia and epilepsy was found to have pulmonary emboli during one of many admissions for falls, thought to be due to his epilepsy. He was reviewed in Papworth hospital and life-long anticoagulation was recommended, despite his falls, as further clots were highly likely if this was stopped.

A month later a haematologist decided to stop anticoagulation, worrying that he might bleed if on blood thinners and having falls. He died a year and a half later of a pulmonary embolus.

What these three cases demonstrate is that the typical symptoms of pulmonary embolism are not always helpful in people with Down's syndrome who may lack the ability to clearly describe their symptoms. Further, the management of known clots may be biased by perceptions that anticoagulation is too much trouble for those with learning disabilities.

Clotting problems may be being overlooked in people with Down's syndrome. If you know of other people with clots in the lungs we would like to add those to our case files to begin to get a picture of how common this is and whether it is being treated correctly.

Email info@downs-syndrome.org.uk or call 0333 1212 300 and ask to speak to a member of our Helpline team.

Awareness Week 2019

It was another fun-filled, sock-selfie sharing and wonderfully vibrant Awareness Week! So many people got involved – from selling cakes, to jumping out of planes and dressing up their pets. We sold around 12,000 pairs of #LotsofSocks this year... and had 350 requests for our fundraising pack. Thank you to each and every one of you that helped spread awareness and made sure #LotsofSocks was trending on social media... we couldn't have done it without you.



Leave No-one Behind

This year's World Down Syndrome Day theme was 'Leave No-One Behind'. It was a real message of inclusivity, spreading the message that every single person with Down's syndrome should have the same opportunities as everyone else, in EVERY area of life.

Throughout the week, we celebrated, raised understanding, and tried to challenge the world at large to be more inclusive.

We were especially keen to highlight the stories of people who care for someone with a dual diagnosis of Down's syndrome and Autistic Spectrum Condition. These parents

and carers often tell us that they feel under-represented in the media and that they sometimes feel they don't 'belong' in either community.

We heard from some exceptional people, including George Bowman who wrote a piece entitled 'Hear Me' and Debbie Austin, a mother, who shared a very honest account of caring for a child with a dual-diagnosis. Both can be found on the 'news' section of our website.



Ruben Reuter, star of BBC's The Dumping Ground and the moving documentary My Life: The Real Dumping Ground joined an international cast and a crew to create a powerful and beautiful film that was released on World Down Syndrome Day. You can



watch the film here:
<http://bit.ly/LeaveNoOneBehind2019>

Ruben was thrilled to be involved in the CoorDown campaign:

“It was a great opportunity for me...I loved meeting the rest of the cast and the crew. I love the film because the message is very strong and really important.”

Our Services Director Gillian Bird presented at the World Down Syndrome Day Conference at the United Nations in New York on 21 March too. She spoke and showed a special film we commissioned about education and our concerns that some learners are being left behind.

You can read more about her visit later on in this issue.



School resources

Our Information Team also published some new resources for schools during Awareness Week. These include a variety of presentations and documents for children and young people with information about Down's syndrome – ideal for an assembly or class. They focus on the fact that all young people have similarities and differences, while being unique individuals. You can see these here:

www.downs-syndrome.org.uk/about/campaigns/awareness-week-2019_2/resources-for-schools/

Social media

The hashtag #WorldDown SyndromeDay trended on Twitter thanks to some big names joining the celebrations. Theo Walcott, Stephen McGann, the Osprey's rugby team, Steph McGovern and Georgia and David Tennant all got involved. On Facebook we reached more than 419,000 people during Awareness Week, smashing last year's total.





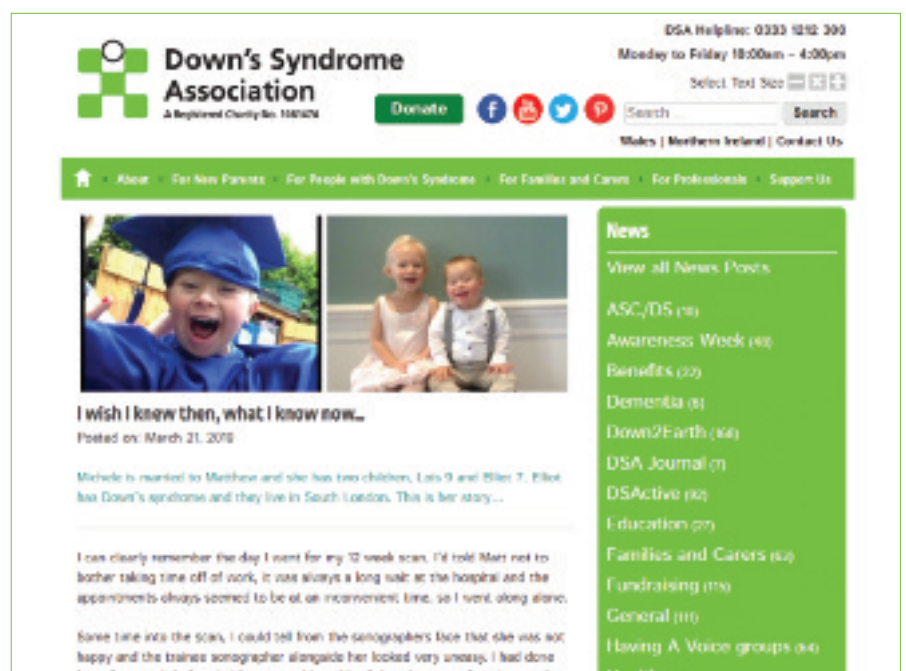
TV and radio

Our very own Fran Austin and WorkFit candidate Chris appeared live on the BBC News Channel, and we managed to get pieces on eight different regional TV programmes, including ITV and BBC.

We helped get numerous pieces in the local press, and Zoe Ball even discussed one of our stories on Radio 2 recently – all great awareness raising.

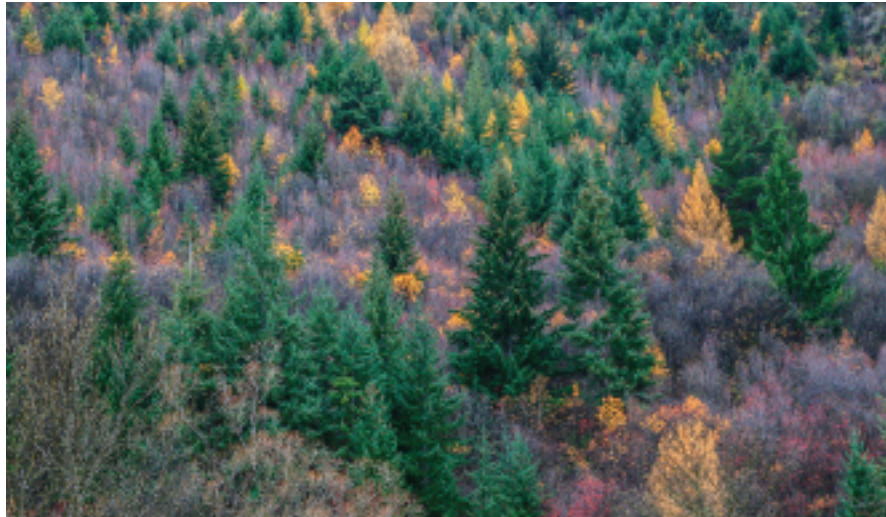
Blogs

We featured 15 new blogs written for us especially for Awareness Week on our website... thank you all for your time and contributions. Go and have a look if you haven't already!



My Perspective 2019

This year's My Perspective award was a little bit different. We had two winners ...one picked by a group of judges and one picked by members of the public.



The People's Choice winner was Carlos Biggemann from New Zealand.

The People's Choice winner, chosen by a public vote was Carlos Biggemann, from New Zealand with his stunning picture 'Autumn Leaves in Arrowtown'. Carlos, who flew over especially for the awards ceremony in London, said:

"I'm so surprised. All I ever wanted was to be here and to win is just so amazing. We travelled about four hours to get this photograph. It makes me feel how colourful life can be, by showing the vibrant colour green, because green represents Happiness, Tranquillity and Peacefulness. How the contrast and the mixture of beautiful colours can represent the season of Autumn. It also makes me want to take more beautiful pictures so I can send more positivity through photos."

The winner of the Judge's Choice award, which is chosen by a group of professional photographers, supporters and people with Down's syndrome was Oliver Hellowell, from Somerset.

He took his exquisite shot 'Blue-tit in the Snow' for his mum, who loves the birds. Oliver is no stranger to the limelight. The 22-year-old has found worldwide acclaim as a nature photographer, has had his own book published, and has appeared on BBC Countryfile and The One Show talking about his love of capturing the great outdoors, and wildlife in particular. He's also no stranger to winning My Perspective, picking up first prize in 2017.



Each year, a special award is presented to a photographer who doesn't live in the UK. This year, Amir Hossein Bagheri from Iran picked up The Stephen Thomas Award for this beautiful image.





The shortlisted photographers were invited to a awards event in the beautiful Normansfield Theatre at the Langdon Down Centre, home of the DSA. It was hosted by patron Peter Davison alongside Carol Boys,

Chief Executive of the DSA.

We'd like to say a big thank you to everyone who entered this year, to our wonderful judges and to our sponsors, Mastercard

and Voucher Express.

In years gone by, people with Down's syndrome were photographed as exhibits; the viewer was not supposed to see the person, just the difference. The Down's Syndrome Association's My Perspective competition turns the camera around and gives people with Down's syndrome the chance to show the world from their point of view.



To see all this year's shortlisted photographers, visit www.downs-syndrome.org.uk/MyPerspective

A golden celebration



In the last fifty years people with Down's syndrome have made amazing strides forward. That's why we want to make 2020, the DSA's 50th anniversary, a year of celebration. We'll be celebrating the stories of people with Down's syndrome who have lived, thrived and succeeded through the last fifty years.

We'll also be celebrating the role that the Down's Syndrome Association has played, and continues to play, in radically changing the landscape for people with Down's syndrome... in education, health, employment, awareness and understanding, and in society as a whole.

In February 1970 Rex Brinkworth began the organisation that is now known as the Down's Syndrome Association.

Do you know someone with Down's syndrome in their 50s or over?

We want to hear their story!

Please get in touch with us if you know a person with Down's syndrome who is aged fifty or over. We would like them to tell their stories or for you to share them with us. We want to know:

- about their lives ... childhood, growing up, adulthood and what life is like now;
- what they love;
- their achievements and the challenges they may have faced and overcome;
- the important people in their lives; and
- what matters to them most.



Visit www.downs-syndrome.org.uk/50Years to find out more.

The DSAActive Health Swap nutrition app is here

Nutrition can be a very complicated issue, with constantly contradictory information being published by the media on a seemingly daily basis. One day chocolate is the villain of the day, the next its potential anti-inflammatory properties could be the cure for a whole range of diseases. One day too much fat is the cause of heart disease, the next it is an elegant solution to obesity. What is clear is that levels of obesity in the population continue to rise, with the latest research suggesting over 25% of the population are clinically obese, and that this is having a negative impact on our overall health.

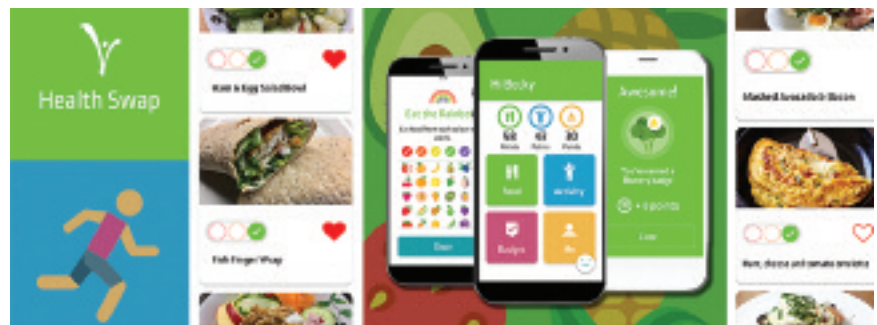
People who have Down's syndrome are more likely to have problems controlling their weight, with figures suggesting that over 70% of people with Down's syndrome are overweight or obese. There are health conditions associated with Down's syndrome that make people with the condition more susceptible to gaining weight. For example, people with Down's syndrome will have a metabolism that's 10-15% slower than someone without Down's syndrome and 15% of teenagers will have an underactive thyroid gland which can lead to obesity. However, research conducted by the DSAActive team shows that there are other factors at play, such as eating behaviours, food shopping, and knowledge of nutrition.

That is where the DSAActive 'Health Swap' nutrition app comes in.

Funded by a grant from the Department of Culture, Media and Sport, the aim of the app is to help people with Down's syndrome make healthier lifestyle choices, improve their physical and mental well-being and enhance their digital skills.

The app has been designed utilising the feedback of people with Down's syndrome, their families and carers, and is specifically designed for the needs of people with Down's syndrome, based on their learning and communication styles.

The app has many different features to help people with Down's syndrome



make positive changes to their lifestyle. The first time the user logs in they complete the 'Me' section, providing a few details about themselves. If you would like more information on how this data is safely stored, please contact the DSAActive team. The 'Me' section is mostly optional but can be a useful way of tracking progress. The activity tracker allows the user to track how much activity they do throughout the week, whether that's playing sport or engaging in physical activities such as walking or swimming.



Throughout the app there are badges to be achieved. These badges act as an incentive towards making positive changes to the users' lifestyle, like trying new activities, being more physically active than the week before, or making good food choices.

The meal planner is the most in-depth feature of the app. Project Delivery Office Guy explains:

"During our research process we discovered that measuring the success of healthy eating by simply cutting calories was neither nutritionally useful nor suitable for the audience. Our principle purpose for the app

is to create easy access nutritionally rich recipes, we like healthy fats, we love our greens and we've tried to avoid too many unhealthy carbs and sugars. We wish to encourage our users to 'Eat the Rainbow' and intend to reward them badges and points for planning, shopping, cooking and eating nutritionally rich meals."

One of the other main purposes of the app is to support people with Down's syndrome to improve their digital skills. So much of our day-to-day living is now dominated by technology, it's often the first thing we see in the morning and the last thing we check at night.

By designing the app specifically for the needs of people with Down's syndrome we aim to develop digital proficiency for people who struggle with technology. The app will be very visual, there will be lots of pictures to support the user, and the text will be simple to read and in a larger font. The format for the app is based on a previous project developing web software for people with Down's syndrome through the ERASMUS project, which the DSA consulted on.

The app is an exciting project for the DSAActive team. We've travelled a long way to get to this point but we are incredibly proud of the app and we can't wait to see what you think about it too. For instructions on where to download the app, more information on the app, please visit the DSAActive website (www.dsactive.org.uk) or email the DSAActive team (dsactive@downs-syndrome.org.uk).

Supporting employment in the heritage sector

By Alison Thwaite, WorkFit Employment Development Manager

One of the things we pride ourselves on at the WorkFit programme is the variety of organisations we work with in a broad range of industry sectors. Since 2012 we have placed candidates into positions in popular sectors such as hospitality, retail and catering.

We have also developed opportunities in finance and law, sport, construction/engineering, science and technology and in public sector organisations including the emergency services, education and arts and heritage.

These successes demonstrate that people with Down's syndrome can succeed in any field with the right support and in a suitable role. One sector where we are keen to expand is the arts and heritage sector. Since 2012 we have developed 14 positions across England and Wales. We wanted to let you know more about what we have done to inspire you to get involved and support us in our work.

Some of our biggest successes to date in this sector have been in Wales. We have developed four voluntary opportunities for candidates in National Trust sites throughout Wales.

Sean successfully volunteered at Bodnant Gardens in 2015 as a gardener and Matthew volunteers as a gardener in Aberglasney.

Hannah has two volunteer positions at the National Trust sites in Plas Newydd and Aberglasney, one in reception and the other in the café.

As well as the National Trust, we have placed candidates into positions in museums in Cardiff and Swansea.

Jack

Jack volunteered at the National Wool Museum Wales between 2015 and 2017 as a museum assistant with duties including organising the woolen display and helping with



retail and reception. The museum enjoyed having Jack work for them, with his supervisor Ann telling us:

"Working with Jack has been a great experience for all the staff here at the museum. It has been great to see him gaining confidence, coming to the museum on a weekly basis and developing in his role".



Matthew

At the National Museum in Cardiff, Matthew has a paid, permanent job

as a Visitor Services Assistant which he combines with working at Frankie and Benny's as a Restaurant Team Member. His role at the museum involves staffing the reception and greeting visitors when they arrive.

Matthew was a guest speaker alongside his employer at the 2017 WorkFit Wales Conference. He told the audience:

"I love working at the museum with so many wonderful colleagues. 12 months ago I had no job and was bored and wondering if I would ever get a job but now with support from WorkFit I have two paid jobs which I love".

Dave Enright, Matthew's manager also spoke, telling us:

"WorkFit has had a major impact at our museum. Over 3 training sessions, more than 40 staff at the museum have benefited from the Down's syndrome awareness training and the feedback from all staff has been wonderful. With WorkFit's support we have been able to develop an opportunity for Matthew initially as a volunteer and then into a paid role. We now feel more confident supporting a person with Down's syndrome and the on-going support from WorkFit has been wonderful".

In the South West our partnership with the National Trust has been very successful. Tom volunteers at The Vyne in Hampshire and Jessica at the Count House in Cornwall.

We are also delighted to support Robert, Cheryl and Katie in their roles at Exeter Museum as Visitor Services Volunteers. They have a wide range of duties including collecting feedback from visitors about their visit and working with museum assistants to deliver events and perform general duties.

In addition, we have also made one placement in the East Midlands and two in the South East of England.



William

William volunteered in 2014 at Hardwick Hall National Trust property in Derbyshire.

Chloe has a paid, permanent job at Ightham Mote which is a National Trust property in Kent and Josh volunteers at the Chiltern Air Museum in Buckinghamshire.

All candidates placed in the arts and heritage sector so far have greatly enjoyed their placements and their employers have found the experience to be both fulfilling and rewarding.

We are keen to expand our reach within arts and heritage as well as in all sectors and we welcome registrations from any organisations who are keen to reap the significant benefits of employing a person with Down's syndrome. All of our support, resources and bespoke training are free of charge and without obligation.

If you'd like to find out more, please give us a call on **0333 1212 300** or go to our website to watch videos of candidates doing their jobs and register your interest if you feel that you may have voluntary or paid work to offer. www.dsworkfit.org.uk <http://bit.ly/workfityoutube>

The Mental Capacity Act (MCA) 2005 and Code of Practice

We've written this article because our Helpline receives a lot of calls about it, from families and sometimes professionals too.

In the past, people with learning disabilities often had decisions made for them. This led to a lack of control in their lives and enabled things like financial abuse and forcible treatment to occur. The MCA attempts to address this situation by providing a common sense approach to supporting people in making their own decisions when they are able and to protecting their interests if they can't make specific decisions for themselves.

The MCA Code of Practice provides guidance for decisions made under the Act. It gives guidance to people who:

- work with people who can't make decisions for themselves
- care for people who can't make decisions for themselves

It says what you must do when you act or make decisions on behalf of people who can't act or make those decisions for themselves. It can be downloaded here:

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

If in doubt, the Code of Practice is a good place to start!

It is important for families to understand the legal framework around decision making for young people in England and Wales once they turn 16. It can come as a surprise to parents to discover that they do not have an automatic right to make decisions for their older teenagers and adult sons and daughters with Down's syndrome.

Key information about the Act

- It empowers people to make decisions for themselves wherever possible.
- It protects people whose capacity is questioned.
- It ensures people are included as much as possible in any decisions made on their behalf.
- It provides a common sense approach.

The Act is based on five key ideas/principles. They are:

- Assume a person has capacity unless it is proved otherwise.
- Take all practicable steps to enable someone to make their own decisions (see supported decision making, below).
- Do not assume incapacity simply because someone makes an unwise decision; in other words, if a person can make a decision themselves, you should not stop them just because you think it's a bad decision.
- Always act, or decide, for a person without capacity in their best interests. There is a formal process for this. The bigger and more important the decision, the more formal the best interests decision making process should be.
- Carefully consider actions to ensure the least restrictive option is taken. If you are making a decision/taking an action for another person that is in their best interests you must try and ensure the act/decision provides the person with as much freedom as possible whilst maintaining their rights.

What does mental capacity mean?

'My brother can't make decisions'

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.

We know that people can have capacity for some day-to-day decisions, for example, but may lack capacity for some bigger and more complex decisions.

According to the MCA, there must be **no 'blanket decision' made about an individual person's capacity**. A person's mental capacity is always assessed on a decision by decision basis. The starting point should *always* be that the person has the capacity to make the decision in question.

- **Key principle of the MCA – 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.**

What is supported decision making?

'Can my son have support to make a decision?'

A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success. This is generally referred to as supported decision making.

- **Key principle of the MCA – People must have support to help them make their own decisions. Types of support could include using alternative forms of communication, providing information in different formats (e.g. photographs, drawings, tapes), having a structured programme to improve a person's capacity to make particular decisions**

(e.g. a healthy eating programme) and having extra time to process relevant information.

This principle is to stop people being automatically labelled as lacking capacity just because they have a learning disability.

When should capacity be assessed?

Capacity assessments should only be carried out if people are having difficulty understanding or making decisions. The assessment should be decision specific and the more serious or complex the decision, the more formal the process should be. Sometimes a professional may be called upon to carry out a capacity assessment.

Someone may be assessed as lacking capacity to make a specific decision if they cannot do one or more of the following:

- Show some understanding of the information given to them.
- Retain the information long enough.
- Weigh up information and use it to make the decision.
- Communicate the decision.

What is best interests decision making?

If the person does not have capacity to make a decision for themselves, their decision maker (holder of a Lasting Power of Attorney (LPA) or their Deputy) would have to make a best interests decision in accordance with the requirements of the MCA.

If the person does not have a decision maker, others (including professionals from social services, NHS or the local authority) would have to decide what is in the person's 'best interests'.

Here are some examples of decisions that may have to be made in someone's best interests if they lack capacity either by their decision maker or the lead professional (e.g. social worker or GP):

- Contact with others.
- Where to live.
- Medical intervention/treatment.
- What care is received.

A best interests decision does not mean cutting out the person with Down's syndrome. Everything should be done to include the person in the best interests process and to establish what their wishes/feelings (past and present) might be.

Their welfare should be looked at in the widest sense and relevant medical/social circumstances considered before a decision is made. The decision must be in their best interests and not in the interests of any other person or the state.

The Best Interests Process

- Encourage participation/find out views: What are the person's wishes? What are their beliefs and values?
- Identify all relevant circumstances.
- Consult others: What do other people who know the person well think would be in their best interests? Family members with an interest in a person's welfare should be consulted by professionals (including social services, NHS and local authority).
- Avoid discrimination and restricting rights; what would be the least restrictive option?
- Weigh up the evidence.

There are informal and formal ways to challenge a best interests decision if you are unhappy with the decision.

As a parent, I feel I'm being cut out of decisions made by professionals about my daughter's care

You do not need to be appointed welfare deputy or LPA to be consulted. If your daughter lacks capacity to make a specific decision for herself, professionals have a duty to consult you as a family

member. Decisions made on behalf of a person who lacks capacity (big and small decisions) have to be made in their best interests. As part of this process family members must be consulted before the decision is made. However, it is important to note they do not have to follow your views if they believe they are not in the person's best interests.

If your daughter has capacity to make a specific decision for herself, you do not have a right to be consulted by professionals. Your daughter can involve you in making the decision as much as she wants to and professionals must respect this.

If you feel that best interests decisions are going to be made without your input, you should raise your concerns with the relevant professional(s), explain your right to be consulted, and ask to be included in the decision making process. We would suggest you put this in writing; you will find links to some examples of template letters (from Irwin Mitchell) you can use for this purpose in the resource section at the end of this article.

What the Act is not intended to do

The Act should not be used by local authorities as an excuse to do nothing. We have heard of cases where people have refused services, for example, and this has been accepted by local authorities because the person is expressing their view and they must be assumed to have capacity.

In reference to such cases the Law Society has commented on the principles of the Act being 'applied perversely' with local authorities using the assumption of capacity to avoid assessing capacity and thus avoiding having to provide support/services.

The Act should not be used to justify poor social or health care. Families have expressed concerns to us over the years about the simplistic manner in which choice is interpreted by support staff leading to concerns over their

loved-one's welfare and health.

The Act should not be seen primarily as a framework for making decisions for, or on behalf of, a person. Rather it should be viewed as a framework for encouraging and maximising participation in decision making.

A few myths:

You must have a LPA (Lasting Power of Attorney) to receive direct payments.

This is **not** the case. Plenty of people with Down's syndrome receive direct payments without family members holding an LPA.

If you do not hold an LPA, you can act as a 'nominated person' or an 'authorised person' for the purposes of direct payments:

- A nominated person is a person whom an adult with capacity to request a direct payment nominates to receive the direct payment on their behalf.
- An authorised person is a person who can request as well as receive direct payments to spend on meeting the needs of an adult who does not have capacity to request direct payments

For further information, see section 12 (Direct Payments) of Care and support statutory guidance – the link is in the resources list.

As the next of kin, I can automatically make decisions for my relative

One of the most common misconceptions we hear concerns the idea that being the 'next of kin' of an adult with Down's syndrome comes with the automatic right to make decisions on that person's behalf whether they lack capacity or not. This is **not** the case and the term 'next of kin' has no basis in law.

This article is a brief look at some of the main issues and themes that families and supporters contact us about. For further information, take a look at the resource list below and/or call our Helpline (Tel: 0333 1212 300).

DSA Resources

Making every day financial, health and welfare decisions post 16

<https://www.downs-syndrome.org.uk/for-families-and-carers/making-everyday-decisions-post-16/>

Information about making choices

<https://www.downs-syndrome.org.uk/for-families-and-carers/teenagers-and-young-adults/making-choices/>

Why is being heard and included in decision making processes important?

<https://www.downs-syndrome.org.uk/news/why-is-being-heard-and-included-in-decision-making-processes-important/?highlight=decisions>

Other Resources

Template letters – Irwin Mitchell

If you are concerned that decisions have already been taken and you were not consulted, then you can use Irwin Mitchell's template letter to register your concern and request a "best interests meeting":

www.irwinmitchell.com/medialibrary/IM%20COM/Home/Activities/Documents/Template-letter-2.doc

If you are concerned that decisions may be taken by professionals without consulting you in the future, you can use Irwin Mitchell's template letter to explain your right to be consulted:

www.irwinmitchell.com/medialibrary/IM%20COM/Home/Activities/Documents/Templateletter-1.doc

Care and support statutory guidance – Dept of Health and Social Care

<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

Let's Talk About Relationships and Sex

The Information and Training Team have spent much of the last year developing a new eight week training course for adults with Down's syndrome covering all aspects of relationships and sex education (RSE).



Whilst most people with Down's syndrome will have had access to some form of RSE at school, the timescales of these do not usually allow for the repetition, reinforcement and depth of teaching needed for people to fully understand some of the complex issues involved.

There is also an assumption with typical RSE that young people will pick up certain things on their own or from their peers, which young people with Down's syndrome are less likely to do. This can lead to a lack of understanding in adulthood, from the practicalities of sexuality and relationships to the laws and rights surrounding them. In response to this need, we have

created a course specifically designed for the learning strengths and challenges of people with Down's syndrome.

This has been piloted by New Key, a care provider in the South West of England. The trainers really enjoyed the process and are very keen to run the course again.

The participants said:

"I enjoyed the course and have found most of it easy to understand."

"I have learnt that it is OK to say no."

"I have learnt not to tell the bus driver about my sex life."

Parents, carers and service providers are supported by a comprehensive trainers guide with weekly slide-shows and a range of visual materials and activities. This new course will be available from October 2019.

For full details about the resources, price and how to order call our Helpline on 0333 1212 300 or email: training@downs-syndrome.org.uk

DSA supporting research

Since the last issue of The Journal we have received a number of reports with findings and updates from research studies supported by the DSA. We've selected the following highlights because they cover subjects that come up quite regularly on our Helpline.

Foot-care and footwear

Dr Stewart Morrison (University of Brighton) surveyed UK-based parents/parental caregivers of children and young people with intellectual and/or developmental disabilities to help understand the foot-care needs of this group of children. The survey was completed by 49 people and the key findings were:

- Foot problems were common with 75% of the respondents highlighting a concern.
- Flat feet were the most common foot-related issue (51%) that parents reported.
- Concern about joint hypermobility was also common (35%).
- 57% of the survey respondents reported receiving foot-care advice for their child but less than half of the parents felt confident in knowing how to manage their children's feet problems.
- Difficulties with finding suitable footwear were reported by 48% of the responders. Over half (55%) didn't know what features to look for when buying shoes.

Parents and carers tell us that footwear fitting is a challenge, often constrained by limited size and width fittings available on the high-street. Dr Morrison has put together a useful list of pointers for parents/carers when looking for shoes for a child:

"It sounds obvious but make sure that the shoes fit and, if needed, can accommodate orthotic devices. Shoe fit is more complicated than it sounds so try and get your child's feet measured at regular intervals. The shape of children's feet develops over-time and demands on the footwear also change. There are many fitting guides and gauges

online and these can be a useful starting point.

Width fitting is a common concern from parents and, if possible, take the time to talk to specialist footwear retailers and understand the options available to you. You may want to consult with the Society of Shoe Fitters or the College of Podiatry for more specialist advice.

The shoes you buy should be comfortable, stable and supportive. Excessive joint mobility in the feet is common in Down's syndrome and you may feel that boots (with some ankle support) are more beneficial. Be mindful of the weight of the shoe. It shouldn't be too heavy. Flat and flimsy shoes should be avoided.

The shoes you buy should have some mechanism for holding the shoe on the foot. This could be Velcro, buckles or laces. This is particularly important if your child is participating in activities".

Tips from parents

A mum posted about her difficulty in finding appropriate shoes for her 15-year-old daughter, who has small wide feet, on one of our Facebook groups. Here are some suggestions from parents:

'We have worn Kickers for years as they are square toed and always have boots as they look trendy even with skirts and gives added ankle support.'

'Hush puppies have great supportive shoes.'

'We usually find Clarks, Start Rite and Ecco go up to a G fitting. M&S kid's shoes are quite wide too.'

'Shoes and boots are always a

challenge although we usually find something in Clark's or Russell & Bromley.'

'He has wide feet so always have to buy bigger size Geox trainers seem to be the best we have found.'

'We have the same problem – It's Uggs, Crocs and Birkenstocks for us.'

'I buy Skechers trainers for my daughter, and sandals. Her basic shoes I get from Clarks when they aren't too childish.'

'Same problem, my daughter is 19 and size 1 again extremely wide feet. She also needs insoles so her shoes are made to measure by the NHS orthotics. Hard work but impossible to buy off the shelf.'

'Puma have a great series of trainers that are wide fitting and Velcro fastening, my sister who is 25 and has DS and teeny feet loves them.'

'We find Converse boots as you can buy a bigger size but fits foot nice. Also Nike children's trainers.'

'Doc Martens are great and you can get Velcro style shoes from them. Very trendy. My daughter is 16. Also Converse boots as you can tie them up and give support. We've recently been looking for prom sandals and actually got a pair on Amazon. Cheap and cheerful but fit.'

'I have just bought my daughter a great pair of sandals from Joules Otherwise it's mainly crocs for easy day to day wear / kickers.'

'We've bought from Primark for trendy trainers, Ugg because they do small sizes and different widths, expensive but bought from a designer outlet and saved a fortune. Bought prom shoes from Clarks but had

to buy children's ballet shoes.'

'ASOS do wide fit that start from size 2 in some styles. They do free returns so you can order a few and get free delivery and won't cost anything to try them.'

The following resources are free to download at our website:

Orthopaedic Issues – DSA Health Series

Orthopaedic Problems (for GPs and other health professionals)

Respiratory Tract Infections (RTIs)

People with Down's syndrome are more likely to get frequent ear, sinus, throat and lung infections and are more likely to have complications after infection. However, because adults and children with Down's syndrome are rarely included in research studies, we do not know the best way to manage these patients to prevent and treat their infections.

In an attempt to address this lack of evidence, Dr Logan Manikam (King's College, London and University College London) has analysed anonymous 2010 data from GP and hospital records looking at

the management of RTIs in people with Down's syndrome including the way in which antibiotics and vaccines have been used and the effectiveness of these treatments. He is currently reviewing similar data from 2015 which he hopes will provide more robust findings on the use of RTI-related health care and the effects of antibiotics for children with and without Down's syndrome.

Dr Manikam will be publishing two separate papers based on his analysis of 2010 data:

"Effects of Antibiotics in Preventing Hospitalisations due to Respiratory Tract Infections in Children with Down's Syndrome"

"Respiratory Tract Infection Related Healthcare Utilisation in UK Children with Down's Syndrome"

We will keep you updated on the progress of Dr Manikam's work.

The following resources are free to download at our website:

Respiratory Infections – DSA Health Series

Recurrent Respiratory Tract

Infections (for GPs and other health professionals)

Current research studies

Please take time to look at our current research page and help researchers where you can www.downs-syndrome.org.uk/about/research-campaigns/current-research-projects/

There are a number of researchers and research teams looking for your support and input including Dr Maggie Woodhouse OBE and her team (University of Cardiff) who are looking at measuring the effect of bifocal spectacles on the ability of children with Down's syndrome to focus at near distance, and to scan complex pictures.

Stop Press – Look out for:

Autistic Spectrum Condition (ASC)

Katie Lambert (University of Surrey) has carried out a research study looking at how parent's and carers adjust to the person with Down's syndrome, for whom they care, receiving a diagnosis of ASC. Katie is currently writing up her findings which we will share as soon as we are able.

Down's Syndrome and Leukaemia

Dr Rhian Thomas and Dr Jill Ellis

Introduction

Leukaemia is a type of cancer that results in large numbers of abnormal white blood cells. These are the cells that are responsible for fighting infection in the body. Although the condition is rare it is more likely to develop in children with Down's syndrome when compared to other children in the general population.

Leukaemia is a life-threatening disease but with modern

chemotherapy and other treatment there is a good outcome for many children with this diagnosis.

This article will explain the different types of leukaemia including the symptoms these diseases cause and how they are treated in children.

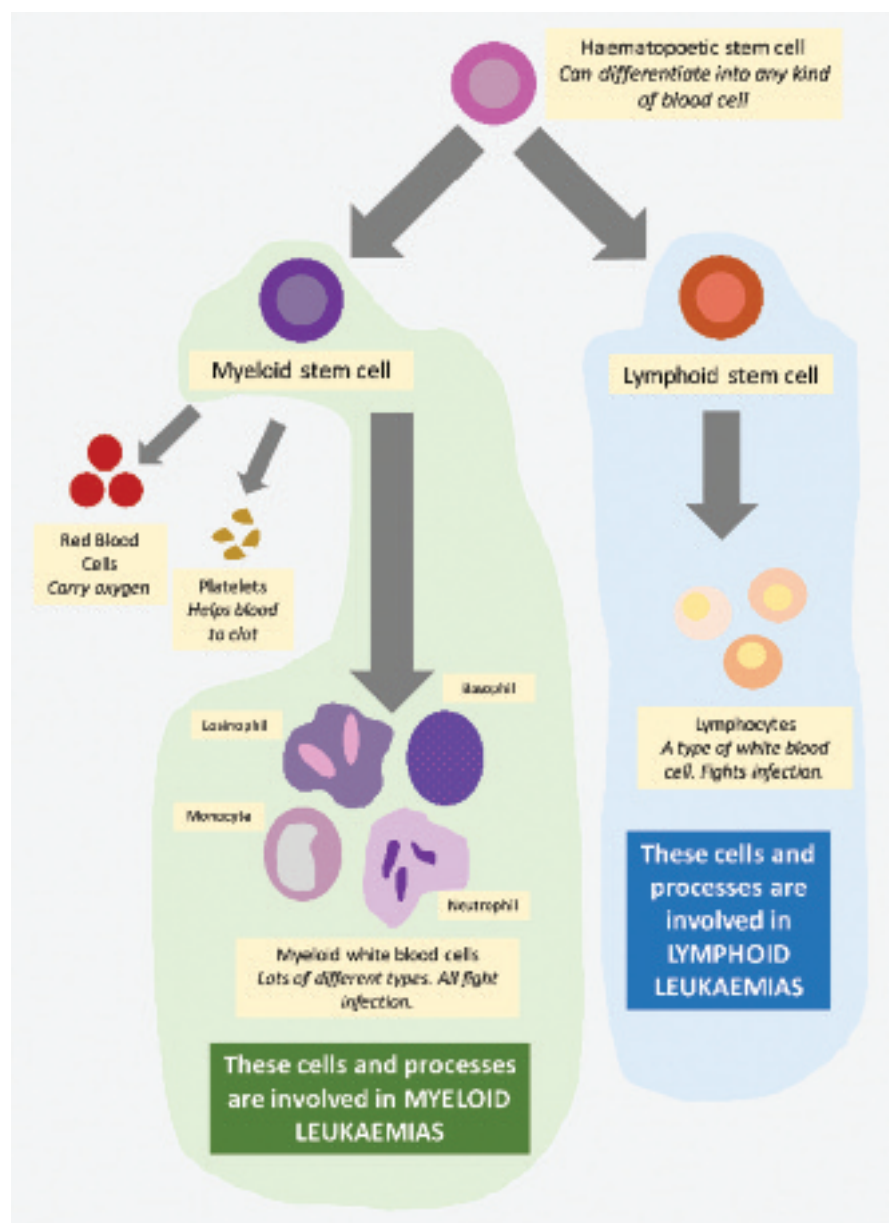
Background information on blood cells

Blood cells are produced in the bone marrow from immature stem

cells. These stem cells are modified as they mature and develop into a variety of specialist cells with different functions. This maturation process is called haematopoiesis and it produces two different groups of cells – called myeloid cells and lymphoid cells.

Each group contains several different types of blood cell that each have different functions to keep you healthy – see diagram opposite.

Haematopoiesis



Leukaemia

Leukaemia occurs when this maturation process goes wrong and large numbers of immature cells called blasts are produced. These blasts are present in the blood stream in high numbers and can be seen when blood is looked at under a microscope. Other blood cells that are normally produced may be present in reduced numbers so children can be pale and bleed more easily.

Those affected can have no symptoms initially but can become generally unwell and develop

enlarged lymph glands, liver or spleen and other symptoms. All people with leukaemia are seen in specialist centres to confirm the diagnosis and their treatment depends on the specific type of leukaemia that they have.

Types of leukaemia seen in children with Down's syndrome

Firstly, leukaemia is classified by the way the child presents; if the onset is quick it is named an acute leukaemia and if slow then it is called chronic leukaemia. Acute leukaemia is by far the most common in children with Down's syndrome.

The second classification is based on the type of cell that is involved. If this process happens in a cell from the myeloid line, the leukaemia is called myeloid leukaemia and if it happens in the lymphoid line then it is called lymphoid leukaemia. Both Acute Myeloid and Acute Lymphoid Leukaemia occur in children with Down's syndrome more commonly than in the general population and have roughly equal incidence. As the presentation, management and outcome vary between the two conditions we will discuss them separately.

In addition, some babies with Down's syndrome may have a unique condition called Transient Leukaemia of Down syndrome (TL-DS). This is a pre-leukemic syndrome and occurs in about 4-10% of new-born babies with Down's syndrome. Babies with TL-DS have an increased chance of developing Acute Myeloid Leukaemia in early childhood.

Acute Myeloid Leukaemia in children with Down's syndrome (AML)

Children with Down's syndrome are more likely to develop AML compared to children without Down's syndrome. Most commonly AML develops in children under 4 years of age with the average age at diagnosis of 21 months. This type of AML is often linked to a specific genetic abnormality in the blood cells genes called GATA1 that is only seen in children with Down's syndrome. (We will talk more about GATA1 in the section about TL-DS at the end of the article.)

Sometimes it may be hard to detect the symptoms of AML which can be subtle initially and develop over time. Symptoms may include enlarged lymph glands and/or enlarged liver and spleen, fever, increased bleeding or bruising. Children with this condition are referred urgently to Paediatric haematology and sometimes admitted to hospital for diagnosis, which will include blood tests and a bone marrow aspirate. They may also have scans and other

investigations to document the extent of the body that is involved.

Treatment usually involves several courses of chemotherapy over many months. With treatment, AML in children under 4 years has a very good outcome. A study in 2006 found over 90% of children with Down's syndrome recovered from AML with few complications following low dose chemotherapy.

Children who are older than four years at the age of diagnosis with AML often have a variation of AML which sadly does not respond as well to treatment and event free survival only occurs in one third of these children.

Acute Lymphoid Leukaemia in children with Down syndrome (ALL)

In the general population ALL is the most common of all childhood malignancies but thankfully is still a rare condition affecting less than 1 in 5000 children. Children with Down's syndrome have an increased risk of developing ALL which is estimated at about 25 times more than those without Down's syndrome. There is thought to be a link between the extra copy of chromosome 21 and the development of this disease, but it is not fully understood and is still being researched.

ALL occurs slightly later in life than AML with an average age of onset at 4.5 years. Children can present with symptoms similar to those seen in AML such as pallor due to anaemia, infections, increased bleeding resulting in bruising and a rash or bone pain.

There are several different subtypes of ALL that have different prognoses and the treatment regimes can vary depending on the specific type of leukaemia. Where possible, children will be asked to participate in current clinical trials so that we can learn more about the best treatment for children.

Previously children with Down's syndrome who had leukaemia

were reported to have reduced survival rates when compared to other children as they were more prone to the side-effects of the chemotherapy such as infections. However, more recent studies have shown that with some specific treatment modifications to reduce toxicity, the survival rate in children with Down's syndrome is improving and approaching that of the general population.

Transient Leukaemia of Down syndrome (TL-DS)

Between 4-10% of children with Down's syndrome will be born with a blood condition called TL-DS. It is also known as Transient Acute Melioidosis (TAM) or Transient Myeloproliferative Disorder (TMD). It is similar to Leukaemia but is a temporary condition that usually resolves without any treatment as the baby gets older.

This disorder is only seen in babies with Down's syndrome and is caused by a gene abnormality in the blood cells, called GATA1. The gene abnormality causes disruption in the maturation of cells in the myeloid line and babies are born with abnormal cells in their blood, like those seen in AML.

Sometimes babies can be unwell with this condition and doctors examining the baby may pick up a large liver or spleen, see a rash or find that the liver isn't working properly with blood tests. But usually babies with TL-DS will not have with any symptoms and the condition can be missed if the baby is not tested for it.

In over 80% of cases TL-DS resolves without any treatment by 3 months of age. A few babies, who are more severely affected, may need treatment with chemotherapy. Children with TL-DS usually respond well to therapy and most recover fully from this condition.

Why TL-DS is important?

Babies who have TL-DS are at increased risk of developing leukaemia in childhood. The exact

numbers vary in the literature but about 20% of children with TL-DS will go on to develop AML under the age of 4 years.

Neonatal Guidelines produced by the Down Syndrome Medical Interest Group (DSMIG) in 2018 recommend that all children with Down's syndrome have a blood test called a full blood count and a blood film taken in the first 3 days of life. (This blood test is often taken at the same time as the genetic blood test which confirms the Down's syndrome diagnosis.) If these tests show high levels of blast cells, then further tests can be done to look at the GATA1 gene to make the diagnosis of TL-DS.

All babies with TL-DS should be referred to a haematologist and followed up with regular blood tests for the first 4 years of life. This hopes to identify leukaemia early and so improve the outcomes of any treatment.

Long term outcomes for Children with Down's syndrome and Leukaemia

A recent study followed up children who had been diagnosed with different types of leukaemia. They found that children with Down's syndrome and AML have better outcomes when compared to children without Down's syndrome who have this condition. It also found that people with Down's syndrome are less at risk of developing other "secondary cancers" as a long-term complication of treatment.

Adults

There is some debate on whether the increased risk of leukaemia continues into adulthood, but the research evidence is limited. One study of 2814 Danish individuals with Down's syndrome found no cases of leukaemia after the age of 29, suggestive that the risk decreases significantly in later life. Adults with Down's syndrome have a significantly reduced risk of developing cancer generally when compared to adults without Down's syndrome.

Summary

Leukaemia occurs when there is an abnormality in blood cell development. It is a rare condition that can occur in any child but is more common in those who have Down's syndrome. Although this is a serious disease, with current medical knowledge and treatment long-term outcomes have significantly improved over the last 20 years. Testing at birth can identify babies with Down's syndrome who are at increased risk so that they can have appropriate follow-up and earlier treatment.

It is worth remembering that although Leukaemia is more common in Down's syndrome it is still a rare disease and most children with Down's syndrome will not develop this. However, if you are worried about any unusual symptoms it is always best to discuss your concerns with your GP.

Dr Rhian Thomas ST3 Paediatric trainee

Dr Jill Ellis Consultant Community Paediatrician

Homerton University Hospital NHS Foundation Trust

DSMIG was established in 1996 by 17 paediatricians. It has grown to become a network of approximately 160 healthcare professionals from the UK, Republic of Ireland and further afield. Our aim is to help promote equitable provision of medical care for all people with Down syndrome in the UK and Ireland by disseminating a wide range of information about the medical aspects of the syndrome and promoting interest in its specialist management. We are a registered charity and are the only organisation to provide this type of medical-specific service in the UK. We receive no statutory funding.



www.dsmig.org.uk

Sleep problems in adults with Down's syndrome and their family carers: Research update

Dr Rebecca Stores
School of Health Sciences and Social Work
University of Portsmouth, UK

Background

Sleep disturbance is common and can have harmful psychological and physical effects. People with a learning disability are at a particularly high risk. While sleep disturbance in children with Down's syndrome has received some attention, relatively little has been written about adults with Down's syndrome, especially those of an older age.

The limited amount of research that has already been conducted on adults with Down's syndrome has tended to focus on a fairly limited number of sleep problems. High rates of sleep disordered breathing, especially obstructive sleep apnoea (OSA), are reported in adults with Down's syndrome, but other sleep disorders tend to have been ignored or are referred to only vaguely. It is important to obtain information on the wide range of possible sleep problems to have a better understanding of the area.

Also, additional conditions that an individual may have can contribute to the causes of sleep disturbance and this is rarely mentioned in studies of adults with Down's syndrome. Several physical and psychological conditions are associated with disturbed sleep and many of these conditions are reported to be common in individuals with Down's syndrome. Examples include heart disease, thyroid disease, epilepsy, being overweight, anxiety, depression and dementia.

In addition, caregivers' ability to

cope with an individual's sleep disturbance should be explored as their ability to do so and general wellbeing may be impaired by their own lack of sleep.

New research study

With these issues in mind, we carried out a new research study on sleep in adults with Down's syndrome. This research aimed to:

1. describe the range of sleep problems in adults with Down's syndrome and how common they are from the perspective of family carers,
2. explore associations between sleep problems and age, gender, body mass index, level of intellectual disability, daytime sleepiness and general health and wellbeing,
3. explore possible sleep problems of family carers and other family members to see whether their sleep is affected by their relative with Down's syndrome, and
4. obtain information from adults with Down's syndrome themselves about their sleep.

Who took part in the research and what did it involve?

The research consisted of two surveys, the first completed by family carers of adults with Down's syndrome aged 16 years or older and the second, by adults with Down's syndrome themselves (with assistance from carers, relatives or friends where appropriate).

The survey of family carers was

completed by 100 family carers recruited through the UK Down's Syndrome Association via their electronic newsletter, blog, Facebook and Twitter accounts where a short article about the nature of the research was provided together with links to the online survey.

The survey of adults with Down's syndrome was completed by 68 individuals aged 16 years and over recruited through the Down's Syndrome Association via the Association's Down2Earth group, electronic newsletter, blog, Facebook and Twitter accounts where a short article about the nature of the research was provided together with links to the online survey. Instructions and a study information sheet was provided at the start of the survey which was in easy read format (Figure 1).

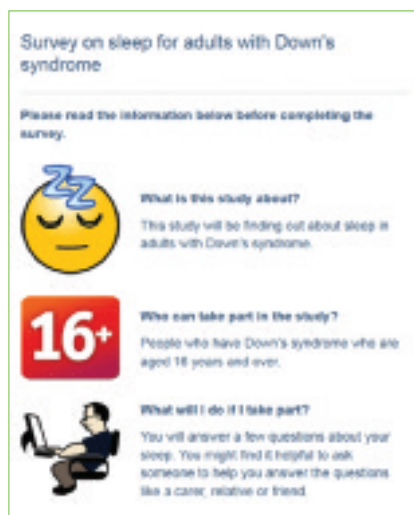


Figure 1: Easy read instructions and study information sheet for online survey

Respondents were advised they might find it helpful to ask someone to help them answer the questions such as a carer, relative or friend.

What did the surveys ask about?

The survey of family carers, provided a comprehensive account of the sleep of adults with Down's syndrome by asking about the individual's general sleep habits, a wide range of sleep problems and how common they are, daytime sleepiness and any treatments for sleep problems that were currently being used or had

been used in the past month.

Additional information was collected about the individual's general health and wellbeing and any possible difficulties experienced by carers such as effects on their own sleep and general wellbeing. It took carers around 20-30 minutes to complete the survey.

For the survey of adults with Down's syndrome, information was collected from adults, with assistance from a carer, relative or friend where appropriate, using a separate online or paper questionnaire. Questions asked about a range of sleep problems including whether or not the individual has problems getting to sleep, night time waking, waking early, nightmares and daytime sleepiness and how such problems make them feel.

Findings

Survey of family carers

The main findings from this survey were:

- High rates of a wide range of sleep problems were reported. These included problems getting off to sleep or staying asleep, other problems and behaviours during sleep, features associated with obstructive sleep apnoea and sleep related problems and behaviours occurring during the day. The percentage of adults reported as having each sleep problem or behavior is shown in Table 1.
- Rates of occurrence were similar to those in a group of children with Down's syndrome studied previously by the author (Stores et al, 1996) suggesting problems may persist into adulthood.
- The occurrence of sleep problems was not associated with age, gender or level of intellectual disability.
- High rates of excessive daytime sleepiness were found with 38% of individuals falling into clinically significant categories.
- Significant associations were found between sleep problems

and body mass index, excessive daytime sleepiness and a range of health and psychological/behavioural problems.

- Low rates of treatments for sleep problems were reported.
- The majority of family caregivers (58%) felt their own sleep was affected by the sleep of their relative with Down's syndrome as were other family members. Responses indicated the considerable impact this had in some cases.

Survey of adults with Down's syndrome

The main findings from this survey were:

- High rates of self-reported sleep problems of different types in these adults including problems getting to sleep, night waking, difficulty getting back to sleep, early waking, problems with breathing and being sleepy during the day (Table 2).
- Other individual responses related to feeling insecure, needing the toilet, restlessness, pain and thoughts about family members.

Implications

Sleep problems in adults with Down's syndrome are common and varied. Efforts are required to increase awareness of sleep disruption generally in adults with Down's syndrome including making individuals aware that poor sleep is not an inevitable aspect of the condition, but is potentially treatable.

Assessment and treatment of sleep problems should be offered to all adults with Down's syndrome to help improve quality of life.

It is important that help and advice is sought if someone with Down's syndrome is experiencing sleep problems.

The first port of call should be their GP. If appropriate, they will refer on to other professionals with experience of sleep problems such as a sleep clinic.

Table 1:

Percentage of adults with Down's syndrome reported as having sleep problems or behaviours by family carers (n=100)

Sleep problem/behaviour	'Daily' or 'Several times a week' (%)	'About once a week' or 'About once a month' (%)	'Never' (%)
Disorders of initiating and maintaining sleep			
Problems settling at night	37	27	35
Awakens during the night and requires attention	33	26	41
Very reluctant to go to bed	30	19	50
Wakes before 5 in the morning	11	30	58
Reluctant to go to bed because of fears	7	12	81
Other problems/behaviours occurring during sleep			
Teeth grinding	39	14	47
Sleep talks in his/her sleep	26	40	33
Rolls from side to side rhythmically during sleep or while going off to sleep	12	10	78
Complains of nightmares	7	20	73
Bites tongue during sleep	4	1	95
Night terrors	2	6	92
Sleep walks	1	5	94
Head during sleep or going off to sleep	0	2	98
Features associated with obstructive sleep apnoea			
Breathes through mouth rather than nose	84	9	7
Snores loudly in bed	53	28	19
Restless sleeper i.e. moves around a lot in bed	48	24	27
Sleep with his/her head tipped right back	43	9	49
Sleeps in unusual positions	40	15	45
Appears to stop breathing for up to 30 seconds	35	17	49
Appears to have difficulty breathing during sleep	33	14	53
Sweats a lot during sleep	21	14	65
Gags or chokes during sleep	7	13	80
Complain of headaches on waking up	3	15	82
Makes quick movements of the arms and legs (e.g. kicking or flailing)	3	10	73
Wets the bed during sleep	3	10	96
Sleep related problems or behaviours occurring during the day			
Lacks energy during the day	45	31	24
Excessively sleepy during the day	38	35	28
Irritable during the day	33	31	36
Difficulty staying awake during the day	30	28	43
Actually falls asleep during the day	26	32	41
Take naps during the day	25	24	49
Drowsy during the day	25	22	53
Miserable during the day	21	34	56
Irresistible sleep attacks	16	13	70
Appears more active than others during the day	14	23	63
Become so weak that he/she falls to the ground or has to lie down before falling, usually in response to laughing or crying	1	3	97
Feeling of being paralysed upon awakening, even though he/she is aware of his/her surroundings	0	1	99

Table 2:

Responses to survey items for adults with Down's syndrome (n=68)

Survey question	Yes	Sometimes	No
Do you sleep well?	26 (39%)	29 (43%)	12 (18%)
Do you have problems getting to sleep at night?	20 (29%)	18 (26%)	30 (44%)
Do you wake up in the night?	24 (36%)	31 (46%)	12 (18%)
If you do wake up in the night, do you find it difficult to go back to sleep?	24 (36%)	17 (25%)	26 (39%)
Do you wake up early in the morning (before 5am)?	15 (22%)	19 (28%)	34 (50%)
Do you have scary dreams?	6 (9%)	17 (26%)	43 (65%)
Do you find it hard to breathe at night?	17 (25%)	15 (22%)	35 (52%)
Are you sleepy during the day?	22 (32%)	29 (43%)	17 (25%)
Do you have naps during the day?	13 (19%)	27 (40%)	27 (40%)
Do you get angry if you cannot sleep?	13 (20%)	9 (14%)	43 (66%)
Do you think you have any other sleep problem?	14 (21%)	n/a	54 (79%)

How will the research findings be disseminated?

A detailed account of the finding of the survey of family carers has been published in the Journal of Applied Research in Intellectual Disabilities (JARID). The findings will also be shared in other publications for professionals and presented at research conferences and specialist meetings with the aim of publicising the importance of the subject for clinical practice and further research.

Who organized and funded the research?

This study was sponsored and funded by the University of Portsmouth and the Baily Thomas Charitable Fund.

Who reviewed the study?

The study was reviewed and given a favourable opinion by the South West Cornwall and Plymouth NHS Research Ethics Committee (REC Reference No: 16/SWE/0055).

For further information:

If you would like further information about this research, please contact:

Dr Rebecca Stores

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Rebecca Stores is a Senior Lecturer at the School of Health Sciences and Social Work at the University of Portsmouth. She has carried out previous research on sleep disorders and psychological functioning in specific groups including children with Down's syndrome and other forms of learning disability.

Sources of support for sleep problems include:

British Sleep Society
<https://www.sleepsociety.org.uk/>

The Sleep Apnoea Trust
<http://www.sleep-apnoea-trust.org/>

Cerebra
<https://www.cerebra.org.uk/>

Down's Syndrome Association
<https://www.downs-syndrome.org.uk/>

Sleep Scotland
<https://www.sleepscotland.org/>

Leave No One Behind in Education:

Including All Children and Young People

World Down Syndrome Day, United Nations New York, 21st March 2019

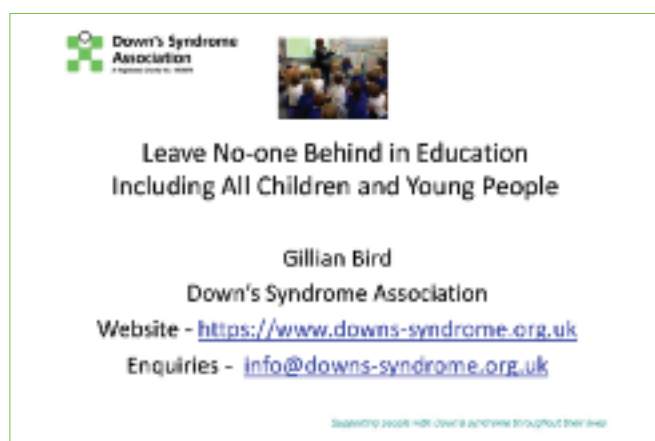
Gillian Bird, DSA Services Director

Earlier this year I was invited to join speakers from around the world at the United Nations in New York on World Down Syndrome Day. Our subject was how to facilitate the teaching of people with Down's syndrome of all abilities in an inclusive education system.

My brief was to outline the learning profile, make recommendations about how learners with complex needs can be included and to give examples of how inclusive practice has created opportunities and improved overall quality of life ... all in just 8 minutes!

I chose to summarise practice developed over the last 35 years; to say how I thought learners with the most complex needs could also be included (they rarely are); and to raise awareness of our concerns about segregation from around the age of 14 years, which seems to be increasing.

I wish to thank Jake Binns for speaking about his preferences in a short film that completes the presentation. We thought you might like to see the presentation slides and accompanying words. Be sure to watch the film too.



Down's Syndrome Association
Supporting people with Down's syndrome throughout their lives

Leave No-one Behind in Education
Including All Children and Young People

Gillian Bird
Down's Syndrome Association

Website - <https://www.downs-syndrome.org.uk>
Enquiries - info@downs-syndrome.org.uk

Supporting people with Down's syndrome throughout their lives

"Learners who have Down's syndrome have been educated in inclusive schools since the mid 1980's in the UK; a long time. We know a lot about how to include learners in mainstream schools successfully and about the significant benefits for outcomes and employment from doing so.

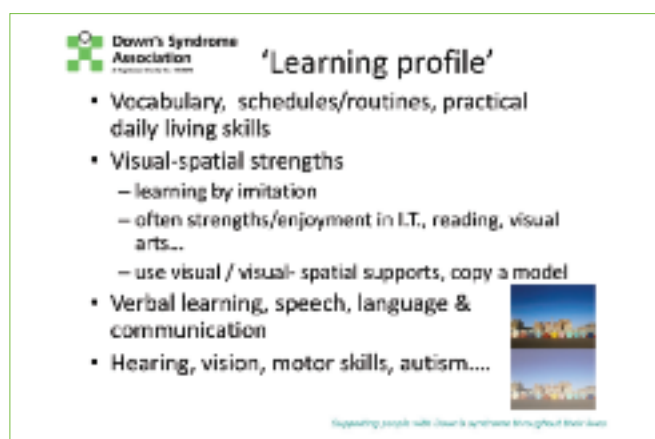
Most learners who have Down's syndrome start school at their local mainstream primary school, although some move to special schools mid primary. Far fewer learners progress to mainstream secondary school.

It is still not common knowledge among members of the public, the non-education workforce who support families or all teachers or education professionals that learners with Down's syndrome do better in positive, inclusive schools.

We will now look at what has helped and what still needs to be done.

It has been beneficial for teachers to have knowledge about the 'learning profile' of common strengths, such as vocabulary learning, visual-spatial learning, reading, I.T., visual arts, and to know about aspects that may need support, such as working memory, verbal learning, speech, language and communication, motor skills, vision, hearing and autism, and, above all, to understand that learners needs are different.

We can provide information, training and many examples of resources that have helped children and young people to learn. Above are examples of visual and visual-spatial supports used to help learners engage, participate, record, follow schedules, and to support listening and remembering. The examples include manipulatives used during learning and writing guidelines that are bold enough for people to see.



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'Learning profile'

- Vocabulary, schedules/routines, practical daily living skills
- Visual-spatial strengths
 - learning by imitation
 - often strengths/enjoyment in I.T., reading, visual arts...
 - use visual / visual- spatial supports, copy a model
- Verbal learning, speech, language & communication
- Hearing, vision, motor skills, autism....

Supporting people with Down's syndrome throughout their lives

Down's Syndrome Association
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Lessons: inclusive practices, objectives, clarity, using pictures, grids/schedules, black pen/linas, visual translation, memory aids, records

Supporting people with Down's syndrome throughout their lives

But successful inclusion needs more than accessible lessons.

Teachers need to know how to support friendships, transitions (changes), how to listen to the learners voice and respect their choices. They need to know they can find solutions, work collaboratively with each other and with parents, and they need to think long term.

There is also the question of how well teachers understand intellectual disability, particularly at secondary stage. In some schools it seems they may not, otherwise teachers would not make unhelpful comparisons with peers who do not have an intellectual disability. Instead, they would be celebrating successes and planning with young people and their parents for the next phase.

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Understanding rights and needs

- Friendships
- Transitions
- Voice, choice
- Gains now and for the future, work, well-being
- Intellectual disability, individual needs

Supporting people with Down's syndrome throughout their lives

How can we create conditions for all learners who have Down's syndrome to be educated at community schools, including those who have very complex needs, who currently are not included in mainstream schools in the UK, or not usually?

We can make more engaging, individual resources (can you see the picture of the coins in sparkly gel bag on the slide?) and teachers can further extend the curriculum, for example, to teach attention, communication and movement through a range of personalised sensory experiences, such as poetry, stories, songs, games, musical experiences and art.

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Creating conditions for all learners

- Inclusion
- Separate classes
- Personalised sensory experiences e.g. poetry, stories, songs, games, musical experiences, art
- Expectations of decision makers

Supporting people with Down's syndrome throughout their lives

Learners who have complex needs may learn in a variety of places and environments, not just in traditional classrooms. These spaces can be created in mainstream schools; there is no reason why they should not be.

But we will need teachers to understand the different needs of learners who have Down's syndrome, as it has been our experience that when schools create separate places for lessons (e.g. bases, units) these can become the 'go to place' for learners who do not need these, who can be included in regular lessons and for whom expectations are too low.

In addition to learners with very complex needs not being included, we have seen an increase in restrictions for learners 14+ at secondary schools. We are seeing students barred from courses that lead to examinations they are not expected to be taking, placed in segregated classes instead.

Down's Syndrome Association
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Leave no-one behind

- Few learners with complex needs included
- Restrictions common for majority of learners age 15 – 19
- Film: Jake, 15, has plans for his future. He wants to carry on learning at his school.

Supporting people with Down's syndrome throughout their lives

I will now show a film of Jake, 15, who attends his local secondary school. He is planning for his future, thinking about what job he might do, and he is expecting to continue his inclusive education into his school's sixth form. This is not a given, as most mainstream sixth forms currently exclude students who have intellectual disabilities; they don't yet offer inclusion on their existing courses or suitable alternative accreditation.

We hope Jake will be listened to and his preferences accommodated, so he does not experience the loss of his peers, so that he is not left behind."

<http://bit.ly/JakesFilmInterview>
with Jake Binns

Gill: "What do you like about school?"

Jake: "P.E., drama, science, food tech, maths, English, photography"

Gill: "So you do cooking?"

Jake: "Cooking, yes"

Gill: "What's been your favourite thing to cook?"

Jake: "Smoothies"

Gill: "And do you cook at home?"

Jake: "Yes, with Dad."

Gill: "Have you thought about what you might like to do when you're older?"

Jake: "When I'm older I could be cooking"

Gill: "So you've thought about that. That's something you might like to do"

Jake: "Yes. Cooking in a restaurant"
"I'm in year 10. When I've done that, end term, I go to year 11. I want to stay in school. Exams, more school, do exams"

Gill: "You've got the rest of year 10, year 11 and then big decisions about sixth form or college. Have you thought about that, what would you like?"

Jake: "Yes"

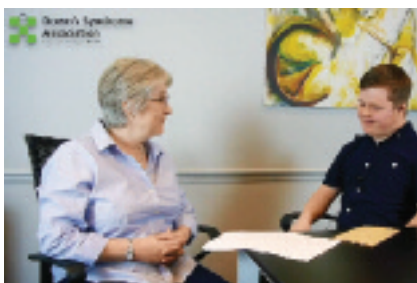
Gill: "What would you like?"

Jake: "I like staying in school".

Gill: "You'd like to stay in your school, and go into sixth form. The school you are at at the moment?"

Jake: "Yes".

Gill: "Thank you for telling me that"



The WDSO presentations and discussion panels can be watched at www.worlddownsyndrome-day2.org/event/wdsd-new-york-2019 and Jake's film is at bit.ly/JakesFilm

"One of my biggest fears when Saajan was born was how he would fit in with the Sikh community"

Harps Kaur

When Saajan entered this world, much to our surprise, he came with a little something extra – he had Down's syndrome.



To say we were devastated is an understatement. The grief and shock that washed over me brought with it a wave of deep devastation as my mind was clouded with misjudgement. We grieved hard for those initial few days, weeks, months, for the perfect baby we thought we were going to have.

I was paralysed with fear as I was told that our lives would "never be the same" and that it would be "hard" by professionals who were basing their advice on outdated assumptions.

I was terrified. I wanted out.

What would our lives be? What did the future hold? What if he is a difficult child? Would he be a burden to Arjun, our eldest son? Would he live with us forever? Would we survive this?

My biggest source of guilt was that I'd wanted to give my eldest son a best friend. Instead it felt like I'd birthed a burden. My heart was broken.

Amidst all the confusion, chaos and grief, Arjun was falling more and more in love with his baby brother. He viewed the world through a clear lens ... no judgement, no expectation. The things I tried to mask that told the world he had Down's syndrome were the same things Arjun was cooing over, like his almond shaped eyes. Watching Arjun love Saajan unconditionally taught us. Arjun loves Saajan so fiercely and is extremely protective of his little brother. He's also his greatest cheerleader and is so excited by the progress Saajan makes.

During our rollercoaster journey of acceptance we rode every single emotion: grief, anger, denial, anguish, depression ... finally coming, months later, to a place of peace.

As time has gone on living examples of people with Down's syndrome have squashed the outdated perceptions and fears that I had. I've learnt that people with Down's syndrome can live independently and achieve so much given the right support – it may just take them a little longer.



People with Down's syndrome are smashing misconceptions by contributing to society more than ever – saving lives – Valerio from Italy saved a girl from drowning a few years ago; starting their own businesses – such as John Cronin who founded John's Crazy Socks, or Collette Divitto's own cookie business after being denied a job; starring in their own TV show – Born This Way; participating in the Special Olympics and thrashing them – Chelsea Werner; and there are even supermodels with Down's syndrome such as Madeline Stuart! More recently huge companies such as River Island and Benefit Cosmetics have embraced individuality through fashion and beauty – a major breakthrough. Such cases fill me with so much hope for Saajan's future. As time is moving on people with Down's syndrome are being recognised more and more for who they are and what they are capable of but we still have a long way to go!

Despite our initial fears Saajan has slotted right in to our family...he is the glue that keeps us all together. He is so much more than just an extra copy of chromosome 21 and he's more like us than different. He loves motorbikes like his daddy, he loves playing hot wheels with his big brother Arjun and he's a foodie like me! His infectious smile and zest for life bring us so much joy and that joy is spread around the

world through social media. He has so many of the traits I wish I could have such as enjoying what's in front of him and just being a happy go lucky kinda guy. He's very caring and loves a good old dance!

Being from an Asian culture I really worried about the reactions of others. How would our families react? Would I be blamed? Would he even be loved? I was grateful that both our families embraced our new journey and were pillars of support and still continue to be. Saajan is the apple of their eye and he is showered with so much love. We are so grateful to have an army of support behind us.

We did have the odd comment such as "we'll pray he'll get better". Though people mean well it insinuates that there is something wrong with Saajan. I use those opportunities to educate people that he's not suffering, he's happy and that Down's syndrome doesn't require a cure.

Being someone who is a believer in God my faith has always remained strong and I have always taken comfort in visiting the Gurdwara (Sikh temple). One of my biggest fears when Saajan was born was how he would fit in with the Sikh community. I struggled to bring myself to go to the Gurdwara as I worried about the stares, the unsaid words and the ignorance. With

time, however, I realised that it was me holding us back. Sometimes the fear and anxiety of how we think something will be is far worse than the actual event.

I had to remind myself of the foundations of Sikhism and all that Guru Nanak Dev Ji (the first Guru) taught: we are all a creation of God and we are all equal regardless of any difference. By reminding myself of this daily I felt more and more comfortable with the idea of taking Saajan to Gurdwara ... he has as much of a right to be there as anyone else.

Initially I'd only take him if my husband was with me...he has always been a lot more confident than me when facing the world, primarily because he isn't scanning for people's reactions! We now go to the temple frequently and I feel as much a part of the Sikh community as I ever have. No one has ever actually ever said anything negative to us at the temple, but I'm aware that as he gets older there may be questions and stares but I'll cross that bridge when it comes. I want the sangat (congregation) to grow with Saajan and to know him for who he is.

He loves going to the temple just as much as me...the enormity of the congregation hall, the harmony of the kirtan and the taste of the langar (free food for all those that visit the Gurdwara). My hope for the future is that he'll participate in seva (selfless service) at the Gurdwara for example by helping to wash the dishes just like his big brother does. I truly believe the Gurdwara and other places of worship are a great setting for people with additional needs to be able to develop life skills.

Recently Sri Guru Singh Sabha Gurdwara, Southall (our "home" Gurdwara) and Ramgharia Gurdwara, Oswald Road have supported us in raising awareness by supporting the #DownRightAmazing campaign that Saajan is a part of. This is a breakthrough for us as although I feel it's harder to educate the older generation, our generation is



certainly more clued on about additional needs and are more willing to learn and in turn more accepting. By having the support

of Sikh temples Saajan will be able to help educate and burst misconceptions and I hope will make it an inclusive environment by embracing all that Sikhism teaches us.

I have worked really hard to train myself not to get too lost in looking into the future and I have high hopes for Saajan. We will be right behind him supporting him in whatever choices he makes for the future. He has an army of supporters behind him. I have no doubt that he will achieve wonderful things but, above all, my desire is for him to always stay happy and content.

He has and will continue to change the perceptions of those he encounters.

He's slowed our lives right down and we are able to really be grateful for all the small things in life. He is exactly what our family needed but we didn't know it. He IS perfect.

He has enriched our lives more than I ever could have imagined on the day he was born. Our lives aren't over – they have only just begun. He has given us a new lease of life. We had a 1 in 1,000 chance of having a baby with Down's syndrome – we were that 1, we hit the jackpot!

Saajan continues to prove to me that my fears were unfounded ... HE is my greatest teacher. We are a pretty regular family, doing regular things and enjoying the ride! I worried about the impact having a child with Down's syndrome would have on my family but he has strengthened the relationship between my husband and I; he has given Arjun the opportunity to become the most well rounded human being; and he has brought us all so incredibly close. Arjun and Saajan are literally each other's breath – they are so close and they play and fight just like regular brothers – I had nothing to fear! Our lives feel full, complete.



'Down2Earth' Magazine Helps Family Meet for the First Time

This is a story of pure coincidence and luck...

Bryony and Jamie discovered that they share a family member, but only because a relative spotted them on the same page of our Down2Earth magazine!

The pair both featured on pages 6 and 7 of the magazine in last year's Autumn/Winter issue. The pair live more than 300 miles apart and had no idea that their mums shared a cousin until, after seeing their stories next to each other in the magazine, the pieces of the jigsaw were put together.

Bryony, who lives in Morecambe in Lancashire and Jamie, who is from Dover in Kent, are both in their 20s. Both were pleased when they were featured in the September 2018 issue.

Bryony had written about her ambition to be a journalist and Jamie's story was about his progress since he had been featured in the magazine 25 years ago as a baby.

The family connection came to light when Bryony's mum Theresa had her cousin Linda to visit. Bryony proudly showed Linda her article in the magazine and Linda instantly recognised the face on the next page. It was Jamie, her (adopted) cousin Sue's son!

They could hardly believe the coincidence. Linda had been adopted by Sue's aunt and uncle in the 1950s and had grown up in the family. She later decided to search for her birth family, connecting with Theresa, her blood cousin.

Bryony said:

"One day when Linda came over and showed her I was in the Down2Earth magazine, she saw someone called Jamie who she recognised as her cousin's son. That was funny because my mum is her cousin too. We were on the same page as each other."

Direct contact was made between the families via text message but the distance between their homes made getting together in person a challenge.

Sue and Jamie happened to be travelling back from a trip to Scotland when a text arrived and soon a plan was hatched – the two families would meet at The Blackpool Football Club, which was a treat that had been booked for Jamie's birthday.

The families only met for an hour, but it was a meeting that will be remembered forever.

Bryony commented:

"I was so excited to go to Blackpool because it's my favourite place, and to meet Jamie who was on the same page as me. We didn't know each other but we both like football. Without Linda we wouldn't have met, two strangers on the same page."

Sue said:

"They just clicked. They were so happy to meet each other. I feel like two families have been united, all because of a magazine. Without the piece in Down2Earth the two families

would be none the wiser of the connections. Since the piece, another cousin of mine and Linda's has been to visit after 25 years of no contact. It's quite incredible how this has come about."

Bryony's mum Theresa said:

"I was surprised and delighted with the coincidence of Bryony and Jamie's stories appearing on the same page of the magazine, and even more pleased to then have the opportunity of meeting him and his parents. It's very special as it connects two parts of my lovely cousin Linda's life in the most unexpected and serendipitous way."

Down2Earth is very pleased to have played its part in making such an amazing story happen!



Corporate Support



SporTedd supports DSActive

SporTedd, a Teddington organisation supporting sport in their local area, has supported us for the first time with two grants of £500 towards our DSActive programme.

"We really appreciate the support of SporTedd as the first grant has enabled us to buy much needed equipment for our new sports sessions, which will be used by the participants with Down's syndrome throughout the summer.

The second grant has enabled us to purchase DSActive uniforms which are so important for us as a team. They allow us to be identifiable when we visit sessions and run events, and they help increase team spirit.

DSActive is the only programme in the country specifically supporting people with Down's syndrome to be physically active, having uniform helps us build our brand, which means that we can support more people with Down's syndrome to change their lives."

Alex Rawle,
DSActive Project Manager.

Running for the DSA

Two of this year's amazing London Marathon #Team21 runners have shared what inspired them to run a gruelling 26 miles for the DSA.

My Eleventh Marathon by Ian Ferguson



I run for the DSA in the London Marathon. Since my niece, Megan, was born with Down's syndrome in 2008, I have run for no one else.

Although I could get a place with multiple charities if I chose to, I only ever submit one application even though there is no guarantee of getting in. However, that's the great thing about running for the DSA... all the people who run the marathon for Team 21 have a genuine connection to the charity. It is almost a privilege to miss out as you know the place has gone to someone it will mean so much to. As luck would have it I have been able to get a place every year, often as a reserve, due to an unfortunate runner withdrawing. This year the call came almost as late as it could have but there I was in April for the 11th year on the trot for my charity.

I used to run with my focus on the stopwatch ... getting a good time

was the great goal. Running for the DSA at London has changed that. It is more important to be a part of something which means a lot to me and my family. It is more important to be one of the DSA team of runners, volunteers or supporters. It is more important to run for them than me. Whether it be supporting the runners in the lead up with advice or tips or encouraging them in the race itself, the end goal of representing the charity and raising valued money for them is the reward.

The highlight of this year's race? It wasn't the crowd chanting my name when I waved at them. It wasn't the sights. It wasn't that I did far better than I ought to have done, bearing in mind my lack of training this year. It wasn't getting the medal round my neck. The highlight was just before halfway, coming off Tower Bridge. Taking the outside line into the corner to go and wave at the crowd, a young boy was stood with his family, hand raised to "high five" any runner who came towards him. I smiled and did so. The boy had Down's



syndrome and seeing him and his family encouraging the runners, and me, reminded me why I head to the start line every year.

I am proud to run for the DSA and thankful to all of the team for their support and hard work, which is of such great benefit.

Me, I just put one foot in front of the other. That's quite easy really.

Running out the Storm by James Bourne

At 2.21pm on 28 April 2019 I crossed the finish line of the London Marathon. I managed a time of 3 hours 58 minutes, which was a little slower than I'd hoped, but given the injuries I'd picked up in my training I was happy to finish in less than four hours.

Like so many others, finishing the London Marathon meant much more to me than just a finish time. The event was symbolic of the journey I'd travelled over the last few years.

Since I lost my younger brother Ben to suicide in 2017 I had struggled with bouts of depression. If you've lost somebody you love to suicide you will know the waves of reflection and guilt can be intense and hard to cope with.

Soon after Ben's death my wife Aimee became pregnant again. We already had two boys, Baxter (6) and Toby (4) and although the news was overwhelming at first, the pregnancy felt like something positive in the middle of a storm.

We had no idea that Robin would be born with Down's syndrome. The scans hadn't picked anything up and it came as a shock when we found out. My knowledge and experience of Down's syndrome was very limited. When I was eight years old, my mum introduced me to Stuart, who was a child with Down's syndrome. We watched wrestling together and I think we might have even pretended the living room was a wrestling ring a couple of times.

Other than the fun I'd had with Stuart, everything else was viewed from afar. After speaking with nurses and doctors in the Women's Hospital in Birmingham my initial feeling was fear ... fear of the unknown. What problems might we face as a family? What will Robin's quality of life be like? Will I be equipped to support my boy's disability? Such life events can throw up worry and selfish thoughts.

This way of thinking didn't help my frame of mind and I'm sad to admit I wasn't there for Robin and my family as much as I could have been. I visited a counsellor for a while but found the process too difficult. Speaking about losing Ben and how difficult life felt overall only made things worse.

After seeing a doctor, I sat staring at the medication I'd been prescribed. It was a wake-up call. Everyone finds their own way out of hard situations and I decided that mine wasn't medication.

I thought about the things that had made me happy throughout my

life ... drawing, Manchester United, wrestling, running ... and I started running again. First it was small laps of Cofton Park, then going to Parkrun each week, next a half marathon. I was enjoying myself. The running gave me clarity. It helped me see clearer.

I saw everything for what it truly was. My little boys were at the centre of this with Robin shining brightly at the very centre. Robin, my beautiful little boy, full of joy and love, waking up to the world. Being around him is truly magical. He struggles like all babies do but when he laughs, smiles or bites my nose I feel how lucky I truly am.

Reading about experiences similar to mine through the DSA website helped me understand that the unknown can be as exciting as it is daunting.

Being part of Team 21 at the London Marathon felt like the perfect way to bring everything together ... to draw a line under a difficult period. That's how it feels now. The marathon is over and so is the storm.



Exeter Golf and Country Club is hosting the 2019 Damon Hill Golf Classic

The DSA and DSI Golf Day with Damon Hill and Michael Caines is coming to Exeter Golf and Country Club this autumn.

Former F1 champion, Damon Hill OBE and Michael Caines MBE, will be jointly hosting a day of golf and an evening dinner for the Down's Syndrome Association and Down Syndrome International at the England Golf award-winning golf course on Friday 4 October 2019.

Damon (who has a son with Down's syndrome) and Michael are both patrons of the charities.

The day will consist of 18 holes of golf with competitions, followed by a 4-course evening dinner, entertainment, raffle and charity auction. The dinner will be created and prepared by Exeter Golf and Country Club head chef, Adam Little, and Michael Caines MBE.



The charities are being supported by Lympstone Manor and other companies with auction lots. Lympstone Manor is donating an overnight stay for two with dinner. Exeter Golf and Country Club is offering three lots including a four-ball golf day with lunch, a full leisure membership for rackets, fitness and swimming and an 'Ultimate Spa Retreat' at Wear Park Spa.

Chris Jones, General Manager of Exeter Golf and Country Club said:

"It's an honour to host this high profile and hugely worthwhile

event. Both charities improve the lives of so many children and adults with Down's syndrome along with providing invaluable support to parents and carers. We always enjoy partnering with Michael for the 7 Chefs Dinner and South West Chef of the Year Award, and so we're delighted to have been chosen as the golf venue for this year's golf day."

For more details, to check availability for this year's event or to register your interest in attending in coming years, please contact Becky Penrose on becky.penrose@downs-syndrome.org.uk

Glow In The Park

DSA and DSI are thrilled to be chosen again as the charity partners for this year's Glow In The Park, being held in Exeter on 9 November.

Glow In The Park is the ultimate night-time neon event, a 5km fun run for families and friends. Dance, walk, jog and run on an epic voyage through 6 glow zones.

Tickets are now on sale. Whilst the charities do not profit from ticket sales, we are encouraging participants to raise funds for DSI and DSA using our event page on Virgin Money Giving (which splits the proceeds 50% to each charity). We will also be present at the event and are looking for 35 willing volunteers to help marshal the course.



For more information about the event go to glowinthepark.co.uk/products/glow-in-the-park-exeter

If you would like to volunteer or speak to Becky, our community fundraiser, contact her on becky.penrose@downs-syndrome.org.uk

Devon to Paris Cycle:

Want to take on an amazing challenge to help us celebrate our 50th Anniversary?

Well, look no further...we have an excellent event planned to mark our golden anniversary that you'll really want to shout about! Join Team 21 and cycle from Devon to Paris on a seven day adventure that you won't forget. Cycling through the gorgeous French countryside, fascinating medieval market towns and finishing at the Eiffel Tower in Paris make this challenge one that surely cannot be missed. To find out more check out our website: www.downs-syndrome.org.uk/DevonToParis



GoSkydive

Our annual World Down Syndrome Day Jump is always a popular event for the Down's Syndrome Association and in our 50th Anniversary year it will be bigger and better than ever before!

On Saturday 21 March 2020 the DSA will be holding an extra special event at GoSkydive in Salisbury where 50 jumpers will take to the skies in support of the charity.

It will be an event for all the family; there will be food, games and music for everyone to enjoy. If you want to get involved and take on this amazing challenge then get in touch with the team on events@downs-syndrome.org.uk to find out more!



Trusts

Even as we develop new projects and services, we are mindful that everything that we do is made possible by the invaluable help of our supporters and partners. Trust income continues to be a vital element of our fundraising activities and the DSA is ever so grateful to all the Trust and Foundation partners who have lent us their fantastic support over the years. We'd like to highlight two who have made 2018/19 extra special!



HELPING
VULNERABLE
PEOPLE
LEAD
BRIGHTER
LIVES

The Big Yellow Foundation

Last year the DSA embarked on a wonderful partnership with the Big Yellow Foundation, the charitable arm of the Big Yellow Company, one of UK's largest self-storage specialists and providers.

Charity has always been at the core of the Big Yellow business model, be it through allocating storage spaces to local charities, or through the fundraising work done by their

fantastic staff. In launching the Big Yellow Foundation, they have gone further in their endeavour to help communities and vulnerable individuals.

The DSA was one of the charities chosen for support by the Foundation in its maiden year, and its support has been nothing short of wonderful. We were fortunate to receive a grant of £10,000 that helped us expand some of our core projects in health and education, increasing the number of beneficiaries that access our services.

In addition to their generous donation, the Foundation has been an enthusiastic participant in our fundraising events, including the DSA's Awareness Week in March

2019. They also joined us in our first ever #Challenge21 in October last year.

The Foundation's head office raised nearly £700, an amount that could potentially fund one specialist training course for families and professionals, or two 1:1 assessments with our clinical psychologist, or one session of Having A Voice, our focus-group platform for adults who have Down's syndrome.

In the last twelve months, our partnership with the Big Yellow Foundation has raised not only our income levels, but also essential awareness about the condition and all the ways we support people with Down's syndrome throughout their lives.



Garfield Weston
FOUNDATION

Garfield Weston Foundation

We would like to thank the Garfield Weston Foundation for its fantastic grant of £25,000 earlier this year.

The Foundation has supported the DSA over many years enabling us to deliver ground-breaking projects, and this year they are supporting one of our key projects, 'Resilient Carers'.

Resilient Carers aims to help build

resilience by alleviating stress and anxiety, addressing isolation and loneliness that can inflict lasting damage on carers' health and wellbeing. The project offers practical support and specialist advice to parents and carers of children and adults with Down's syndrome.

As a care-giver, responsibilities often overshadow much-needed self-care. Primary carers tend to ignore their own well-being whilst looking after their child or ward, which tends to be detrimental to the health of all involved.

The Foundation's one-year grant will go towards providing support and advice via our national helpline on matters ranging from health to education to social care and benefits.

"Looking after yourself" sessions

will be offered by a qualified learning disability nurse who has experience working with families/carers. An accredited mindfulness teacher, she will deliver these sessions as a part of our Complex Needs meetings for parents and families of children with Down's syndrome and complex needs such as Autistic Spectrum Condition/ADHD/ADD/OCD.

We are thrilled to be able to offer such a high level of support to our users and would love to offer our services to a larger number of clients across England and Wales.

If you are a Trustee of a Charitable Trust or Foundation and would like to find out more about how you can make a real and measurable difference to young people with Down's syndrome, please contact us.

Down Syndrome Slovenia

Alenka and Jana Šelih, past and present chairperson, DS Slovenia



Weekend seminar for families with children from 7 to 18 years, Moravske Toplice Spa

Our first steps

Down Syndrome Slovenia began in 1997. It was started by a group of parents of small children with Down's syndrome who met as a self-help group and then decided to found an organisation.

There is a long established and active NGO in Slovenia called "Sožitje" ("Coexistence") that strives for the improvement of both collective and individual care of people with intellectual disabilities and their families, including people with Down's syndrome. The founders therefore decided to set up a "section for Down's syndrome" within Sožitje Ljubljana. Ljubljana is the capital of Slovenia. The Down's syndrome Section existed until 2013, when an independent NGO (non-governmental organization) "Down Syndrome Slovenia" was established.

Since the founding members of the "Section" were parents of small children the first programmes they organized were on early intervention. They were combined with events for families, usually held in hotels over the weekend, and included lectures for parents (while taking care of the children with Down's syndrome and their siblings) and some relaxation activities, like bathing in a spa or at the seaside.

The second issue the "Section" wanted to tackle was securing professional literature on Down's syndrome in Slovenian. Before the establishment of the Section, there were practically no books available in Slovenian on Down's syndrome. Now, at least one book in Slovenian is published every year about different aspects of life with Down's syndrome.

To disseminate information on Down's syndrome, the section started organizing an annual, one day conference on "life with Down's syndrome". Topics covered at these conferences included early intervention, education, early reading skills development, medical aspects and employment.

After two years the "Section" was able to get some funding from the Foundation for Disabled and Humanitarian Organisations, a public foundation securing funds for these organisations. This has become a relatively stable source of funding.



Participants in the program for adults with Down's syndrome, refreshing their academic knowledge, Ljubljana

After a few years of various activities, the following programs have been developed:

Empowering people with Down's syndrome and their families

- One day workshops for families;

lectures for family members and professionals; programs of learning support and physical skill developments for children and youngsters with Down's syndrome.

- Weekend seminars for families with children with Down's syndrome. Three groups of these seminars have been developed – for families with small children; for those with school age children; for families with grown-up children with Down's syndrome.
- Early intervention programs running the whole school year in different places in Slovenia.

Dissemination of information on Down's syndrome to the general public and professionals

We work with other NGOs.

- The union of motorcars "Gold Wing" organized a day event for members of the Section during which our members could ride on motorcycles, enjoy a picnic and music performances.
- The Section prepared an exhibition of photos of people with Down's syndrome in one of the galleries in Ljubljana.
- A group of amateur painters contributed to the Section all the pictures from an "ex tempore" they prepared in the countryside.

Informing and increasing awareness of the general public and publishing

At least one book in Slovenian is published every year about different aspects of life with Down's syndrome.

While we support the publication of works by Slovenian writers it has also been necessary to get books translated from other languages.

We've developed an excellent relationship with an adult learning organization in Ljubljana whose

members, studying German, offered to translate texts from German into Slovenian. They had an expert in special education to take care of the professional terminology as well as another expert who took care of the translation.

With the help of this group we have translated about ten booklets. One of them was a book on early speech development of children with Down's syndrome by Prof. Etta Wilken from Germany. For this work we also got the assistance of researchers from the Department of Education, University of Ljubljana, who reviewed the text. We were also fortunate that the author renounced any royalties.

We've translated other booklets from German published by Deutsches Down-Syndrom InfoCenter who have also very kindly renounced any royalties.

We have also been successful at sharing information on people with Down's syndrome in the media. Newspapers, TV programmes and radio stations have been rather cooperative, especially during World Down Syndrome Day.

Celebrating World Down Syndrome Day

We have used the opportunity of World Down Syndrome Day to raise awareness about Down's syndrome in Slovenia from the start. The leading daily newspapers published interviews with professionals working with us on different aspects of Down's syndrome; the topic was presented on television; the Section organized local events including lectures, sports days and concerts.

In 2008, the President of the Republic of Slovenia organized a reception for people with Down's syndrome and their families as well as for carers and professionals working with them.

Since we became an independent charity in 2013, the President has hosted such a reception twice. These events are covered by the

media and are great publicity

We worked with other NGOs to arrange three big concerts (in 2014, 2015 and 2017) which were broadcast by TV Slovenia and were very well received by the general public. Every year, local concerts are organized in smaller towns in Slovenia as well. We also take part in most of the EDSA (The European Down Syndrome Association) and DSi (Down Syndrome International) activities on World Down Syndrome Day. We believe that public awareness about Down's syndrome has increased a lot during these years.

Academic award for diploma papers

Every two years we award outstanding diploma papers on different topics on Down's syndrome, including special education, legal, sociology and medical.

Becoming an independent NGO – Down Syndrome Slovenia

It seemed a natural development for our group to become an independent organisation in 2013. After this we were able to apply for funds earmarked for an NGO. We could also join EDSA and establish contacts with DSi. We also acquired a new office where we can carry out some of the programs.

Our work broadened and became more diversified. We continued the projects described above while also developing a special program for young adults in the form of a 4 day camp where youngsters take part in everyday activities and learn how to live in nature.

The association established international cooperation with similar organisations in Europe. In this way, we could join a project consortia that applied for (and received) EU funding. Recently we carried out a project on healthy diets, the result of which is an internet program accessible also to persons with Down's syndrome and available in Slovene.

Currently we are involved in two

international projects (Erasmus+) where DS Slovenia is cooperating with related NGOs from Spain, Portugal, the UK and Romania. One is focusing on developing VR (virtual reality) tools that can be used by people with Down's syndrome during occupational training. The other focuses on problems of ageing in people with Down's syndrome.

We are also working on a national program financed with EU funds. It will develop a Ljubljana tourist guide for people with Down' syndrome, will be written in easy language and will be published in both Slovenian and English. We are using the experiences of the SmartGuides program that developed this kind of guide for other European cities.

Future plans

As the demography of the Down's syndrome population is changing the focus of the association's work will shift and we will offer new programmes: a) ensuring sufficient numbers of adapted work places, b) ensuring suitable residential units for adults with Down's syndrome and other developmental challenges that are integrated into the local community.

Last but not least we aim to develop leisure and recreational activities adapted to the needs of older people with Down's syndrome as they have the right to age with dignity just like every individual.



Weekend seminar for families with children up to 7 years, Radenci Spa

Normansfield's Artists in Residence

Outreach Learners with Learning Difficulties or Disabilities (LLDD) Art class



Olwen Geen from Richmond Adult Community College (RACC) teaches art to a group of students with learning disabilities and difficulties at the Langdon Down Museum at Normansfield.

The class has been running for several years and the artwork from each project is then displayed at the RACC and in the Langdon Down Centre. The class is held weekly and the students find

inspiration from the objects around them, both in the theatre and the museum.

In the theatre, students have created collages and paintings of the stage, scenery and internal decoration. The outcome has been a body of work in mixed media. Recently the students have been creating mixed media pieces inspired by the wild birds on the decorated door panels. Olwen says it has been a privilege

to teach them and watch their work develop.

One student, Anna, who works part time in the Down's Syndrome Association office, said she loved being on the course and seeing her friends.

www.langdondownmuseum.org.uk/projects/artists-in-residence-with-learning-disabilities

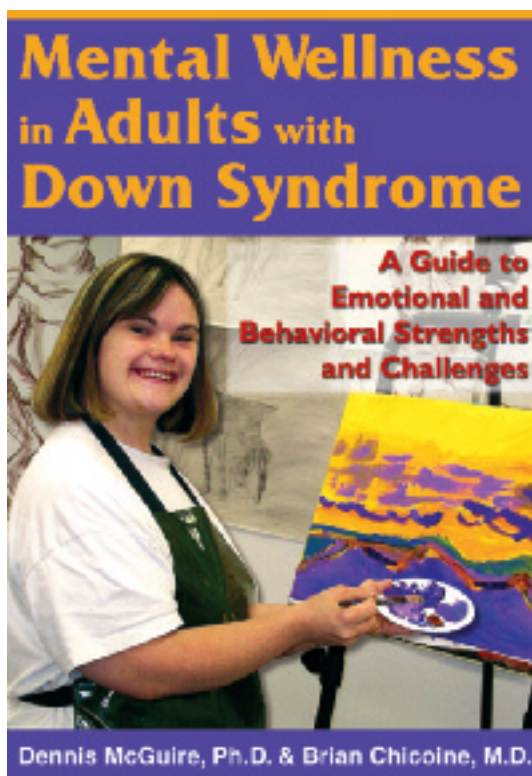
An Information Officer's view – Mental Wellness in Adults with Down Syndrome

'Mental Wellness in Adults with Down Syndrome', published by Woodbine House in 2006, remains one of the most practical and useful commercially published resources for my day to day work.

The authors, Dennis McGuire and Brian Chicoine, co-founded the Adult Down Syndrome Center of Lutheran General Hospital in Park Ridge, Illinois, USA in the early 1990s. At the time it was published, the authors had seen approximately 3,000 teenagers and adults with Down's syndrome at their clinic.

It is written in a positive and readable style and each section is illustrated with real life stories containing practical measures that have helped a person with Down's syndrome in a particular situation. The book contains a wealth of useful information about behaviour, emotional development, strengths and challenges, memory, communication, routines, fantasy and imagination and self-talk. It also has extensive information about supporting mental wellness, identifying mental health difficulties and a variety of interventions to support people to get better.

On first reading 'Mental Wellness' what most impressed me was the authors humanity, their person-centred approach and their focus on the whole person. Over the years I have often found myself reflecting on, imparting, and putting in to practice the information and advice given in this resource both in my role as an advice worker and in my work with DSA's Having A Voice Groups. I have seen a number of supporters and parents have 'light bulb' moments where the information in this resource helped make sense of certain behaviours used by a person with Down's syndrome.



'Mental Wellness in Adults has a lot of information about behaviour. I am taking the book to my next meeting as it explains my daughter's slowness and OCD in detail.'

(written by the parent of a woman with complex needs)

Although published almost fourteen years ago and describing health care within a US context I believe this to be an essential reference tool for families and anyone working with a person with Down's syndrome.

Heads up – Supporting emotional wellbeing – new resources

We are working on a publication to help parents and supporters think about ways to support people with Down's syndrome to feel good about themselves and to arm them with ways of coping when life is challenging.

Emotional wellbeing is about how we think and feel and how we cope with life events. It's also about how we deal with our own emotions as well as those of others. The publication will cover self-esteem, self-identity, recognising emotions, independence, risk and choice, life's stresses and strains, problems and coping strategies. There will be a number of easy read resources for people with Down's syndrome to accompany the publication for parents and supporters. These will be developed with the support of the Having A Voice Groups.

We aim to finish working on these resources by the end of the year with a view to their becoming available in 2020. We will let you know our progress via the Journal, website and social media.



Down's Syndrome Association

A Registered Charity No. 1061474

Helpline and Information Centre

0333 1212 300

info@downs-syndrome.org.uk

Our Information Officers are available to answer calls Monday to Friday, 10am-4pm.

Together with our team of specialist advisers, we offer advice about any aspect of living with Down's syndrome including prenatal support, benefits, education, service provision, rights, health, speech, language and communication, complex and adult needs.

We also offer individual consultations and assessments.

Our information resources are freely available on our website.

People with Down's syndrome shape our resources and help to inform our decisions through our network of Having a Voice® groups.

Parents and practitioners can also ask us questions on our closed Facebook groups.

Contact us for local parent support group details.

Training

training@downs-syndrome.org.uk

We offer training to support individuals at every stage of their lives. From our Royal College of Midwives accredited Tell It Right® study days to conferences, workshops and online training about education and development, positive behaviour support, adolescence, support for adults, Down's syndrome and health awareness, ageing and dementia.



Activities for people with Down's syndrome

Get active

www.dsactive.org.uk

Our DSActive programme aims to provide as many opportunities as possible for people with Down's syndrome to lead active and healthy lives.



Employment

www.dsworkfit.org.uk

Our WorkFit programme brings together employers and jobseekers who have Down's syndrome, providing tailored support to employers and candidates.



LANGDON DOWN MUSEUM OF LEARNING DISABILITY

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



www.langdondowncentre.org.uk



www.ds-int.org

0333 1212 300

info@downs-syndrome.org.uk

www.downs-syndrome.org.uk

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Middlesex TW11 9PS

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

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The more members we have, the stronger our voice

To find out more about our services, campaigns, consultations, research and how you can become a member visit www.downs-syndrome.org.uk