

journal



DOWN'S
SYNDROME
ASSOCIATION

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Disclaimer

The 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 The Journal are those of the authors and do not necessarily reflect the official positions or policies of the Editor or the Down's Syndrome Association.

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Contributing to the Journal

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

We welcome contributions from our members. If you would like to contribute to a future issue please find details on our website:

www.downs-syndrome.org.uk/our-work/information-services/dsa-journal/

Letter from the Chief Executive



Carol Boys

In this Journal we have a great selection of articles including important things to know about some of the preventable medical issues that can affect children and adults who have Down's syndrome. My own experience last year with my son has made me more determined to make sure that everyone who cares for or works with someone who has Down's syndrome understands more about infections in Down's syndrome and how quickly they can become very serious. We will be running regular catch ups with members of the DSMIG.

The Down Syndrome Bill (a Private Member's Bill) put forward by Dr Liam Fox MP is making its way through the House of Lords (at the time of writing). The DSA was not involved

with the development of the Bill but we have been working very closely with the DHSC, providing information and working to ensure that there will be an open and wide consultation on the Guidance that is being developed alongside the Bill. We have been assured by the DHSC that the DSA **will** be involved in any consultation and that we, in turn, will be able to consult with our members in order to feed into the process. It is important that as many views as possible are heard in order to develop Guidance that will make meaningful change for **all** people who have Down's syndrome.

What are your plans for World Down Syndrome Day? We'd love you to join us for one of our Going Forward DSA Update sessions on 21 March. It's a great way to hear about what we're doing and to ask the team questions. The session starts at 9.30am and you can register on our website (downs-syndrome.org.uk/dsa-update-going-forward/).

I look forward to seeing you there in your LotsOfSocks!

Carol Boys, Chief Executive

Letter from Kate Powell



Hello my name is Kate Powell. I am the Down2Earth editor of The Journal.

I am also an ambassador for Down Syndrome International. I have the privilege to speak to ambassadors all over the world.

Our main theme for this year is Inclusion. This has been a very difficult year for everybody. In spite of this I am amazed at the stories in the Journal as they show great skills and perseverance.

Please keep sending us your stories and photos as they give much pleasure and hope that our readers also take advantage of the many programmes set up by the DSA. Dance, keep fit, crafts, cooking and wellbeing. Something for everybody!

Good luck to all of you.

Kate

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On the Cover: Dylan Williams loves cycling and often joins his family for a bike ride round the Welsh hills at the weekend.

News

Awareness Week 2022

Inclusion means...?

We're all missing out if everyone isn't included. That's why for this year's Awareness Week and World Down Syndrome Day, we're celebrating how inclusion improves life for all of us. We want to share what inclusion means to you...go to downs-syndrome.org.uk/AwarenessWeek/ to find out more.

You can also join in the celebrations by purchasing a pair of our **#LotsOfSocks** or taking on **#Challenge21**...you'll find all the details on the site.



Inclusive Education for All

During 2022, we are working with Down Syndrome International (DSi) to run a UK-wide research and advocacy project on 'Inclusive Education', its definition and implementation.

Our research has identified many frequently asked questions from the various stakeholders within the education hierarchy, plus areas where knowledge can be shared.

We will be sharing weekly key messages on the subject of Inclusive Education for all learners, including those with Down's syndrome. We will be distributing concise answers to FAQs, by professionals and people with lived experiences, including self-advocates.

We hope to use these to raise awareness and advocate for long-term system change. We realise that everyone has knowledge and experience in their context, and think that sharing this is beneficial to everyone interested in providing, or receiving, a more inclusive education offer in the UK (and internationally).

To find out more go to: downs-syndrome.org.uk/our-work/campaigning/#education

The My Perspective photograph competition is back

We're thrilled to announce that, after a year's break (due to Covid-19 uncertainty), the My Perspective photography competition is back. Do you like taking photographs? We want to share your pictures and celebrate your view of the world.

Find out all you need to know about the competition on our website at downs-syndrome.org.uk/my-perspective/. Here are some of the short-listed photographs from the 2020 competition.



Well-being Wednesday: online support session

Parenting a child with additional needs is both rewarding and challenging, but can bring additional stresses that impact the parent/carer's well-being.

Finding the time to recharge the batteries can be difficult. Our **FREE** weekly, online Well-being Wednesday sessions offer parents an opportunity to unwind and relax in a friendly and non-judgemental group with people who understand.

The sessions are facilitated by Jane Mitchell who is a Learning Disability Nurse and Mindfulness Teacher, and include guided mindfulness practices as well as other well-being activities, with time to share and reflect.

'The sessions have been sooo helpful. I find I am always more relaxed and calmer immediately after the session. But it's not just a short-term effect. I don't religiously try and practise mindfulness but a lot of what is said in the session often occurs to me and

just acts as a reminder that I can't do it all and actually I'm doing okay.

I find myself mentioning bits of what I have picked up in conversations with friends – i.e. how we are hard wired to remember the one tiny negative thing in a host of positives, and when out walking, I deliberately try to appreciate the colours and sounds around me. The other thing I love about the session is the 'live' nature of them and the fact I am connecting with others. I do sometimes listen to the headspace app but do prefer being linked with others during Well-being Wednesday.'

Anne (parent)

To find out more or to register your place on the next session, go to downs-syndrome.org.uk/our-work/services-projects/training/well-being-wednesday-for-parent-carers/

Actor Sarah Gordy becomes a Patron of the DSA

We were thrilled to welcome Sarah to our team of Patrons earlier this year. The 45-year-old from East Sussex has appeared in countless television productions, including the BBC's *Call the Midwife*, *The A Word*, and most recently, ITV's crime drama *The Long Call*. In 2018, Sarah became the first person with Down's syndrome to receive an honorary degree from a UK university. She was also awarded an MBE, presented by Prince William at Buckingham Palace, for her services to the arts and people with disabilities. She is a fierce campaigner and has been hailed as a role model for challenging attitudes towards people with learning disabilities by her performances – something which she hopes to bring to her role as patron.

Don't miss Sarah interviewing Ann Cleves about *The Long Call* in the new Shifting Perspectives podcast series. (See next page).

Helpline stories: pregnancy and baby

'What will my baby be like when they grow up?'

'I am a midwife. Do you have any information I can provide to parents?'

'Is there anything I should be aware of when it comes to my baby's health?'

With 50 years of experience, the DSA know exactly how to welcome your baby. At our pregnancy and baby online support group, you can meet other parents, ask us questions, and hear from our speech and language therapist.

Our benefits advisor can tell you about the financial support available. We'd love to hear how your new baby is getting on, and we can chat to you about infant development and the basic minimum health checks you can expect.

'Thanks so much for chatting with me today...really appreciate your help and all the reassurance.' – Expectant mother

'Thank you so much. This information is fantastic.' – Screening coordinator



Series four of the Shifting Perspectives Podcast is out now!

We are proud to bring you the fourth series of the DSA's very own Shifting Perspectives Podcast. In this latest series, we hear from award-winning TV and film actor Tommy Jessop about his rise from local theatre, to BBC prime time. We also speak to long-time best friends Clare and Tash about their jobs, hobbies, fundraising challenges, and love of Champagne. Luke joins us to talk about his job as a catering assistant, love of Manchester United, and his lockdown romance, and siblings

Stephanie and Chris chat to Richard about their lives in Northern Ireland, playing tag rugby, and their very special brother/sister bond. We also turned the tables this series and offered up the presenting chair to Sarah Gordy, MBE. Sarah interviews author Ann Cleeves, whose books have featured characters who have Down's syndrome and have been transformed into popular television dramas. The pair also discuss Sarah's recent portrayal of one of Ann's characters in the ITV drama *The Long Call*, and we find out from Sarah what it was like on set.

So, if you haven't listened to the Shifting Perspectives Podcast yet, please do give it a go. Each 20-minute episode hopes

to give you a window into someone's life... raising a smile, providing insight, and delivering engaging content that you can listen to whatever you are doing. There's now 20 episodes to listen to – just search 'Shifting Perspectives Podcast' wherever you get your podcasts.

You can also find all the episodes here: downs-syndrome.org.uk/the-shifting-perspectives-podcast/.

Want to tell your story? We are always looking for new podcast participants to come on and tell us all about their lives. If you are interested, please drop us an email and let us know at dsapress.office@downs-syndrome.org.uk

Professor O Conor Ward

The DSA were saddened to hear of the death of Professor O Conor Ward who passed away in December 2021.

Known to all of us as 'Conor', Professor Ward was a very kind and caring physician who made an enormous contribution to the health of people who have Down's syndrome and other disabilities.

He was a Professor Emeritus of Paediatrics at University College Dublin and a paediatric cardiologist with an interest in sudden death. During his career, he became involved

with children with Down's syndrome who had congenital heart disease and set up a screening programme at a time when this would not have been an option. He became an Honorary Medical Advisor and Patron of Down Syndrome Ireland.

On moving to London, he researched the life of Dr John Langdon Down who first identified the condition of Down's syndrome. His books include *John Langdon Down: A Caring Pioneer* and *Dr John Langdon Down and Normansfield*. With his wife Pauline, he participated as a voluntary

worker in the support of families with Down's syndrome. Professor Ward was a great friend and Patron of the Down's Syndrome Association, and contributed in many ways to its work and the acquisition and preservation of the archive that we hold at the Langdon Down Museum of Learning Disability at Normansfield in Teddington. Conor will be greatly missed by all of us at the DSA.

The DSA Journal intends to publish a longer obituary of Conor in the next edition.

NHS Speech and Language Therapy provision for children who have Down's syndrome

We would like to gain insight into NHS Speech and Language Therapy provision for children who have Down's syndrome living in England, Northern Ireland and Wales.

We are inviting families of children aged up to 11 years of age to tell us about their lived experiences of accessing speech and language therapy for their child.

Please tell us your story, in your own words, if you would like to do so. We may keep your story on file, and may include some stories on our website. We may also share stories with other interested organisations. The stories will be anonymised to protect privacy.

If you would like to send us your story, please email info@downs-syndrome.org.uk.

We are particularly interested to know:

- do you live in England, Northern Ireland or Wales?
- how old is your child?
- describe your child's communication skills
- how often does your child receive speech and language therapy from the NHS?
- has speech and language therapy through your local NHS service helped your child to make progress and to achieve specified outcomes?
- has your child's speech and language therapy had an impact on your family?
- describe your relationship with your child's speech and language therapist

There is no pressure at all to take part.

A busy period of policy work

The last few months have been a busy period in relation to policy work with Government.

A good thing that has come from the Covid-19 pandemic has been the strengthening of our relationships with decision-makers, and especially Public Health teams across England, Wales and Northern Ireland. We have been meeting regularly, sometimes daily, when there was important news to share.

Our *Going Forward* webinar updates have given us the opportunity to get key information to people quickly, and have always involved adults who have Down's syndrome, who, through their involvement with *Our Voice*, have been able to tell Government officials what was important to them.

The prioritisation for Covid-19 vaccines for people who have Down's syndrome, including the addition of children aged 5-11 in January, has been very welcome. At the end of last year it was also announced that new anti-

viral treatments would be available for all those who have Down's syndrome aged over 12 (following a rapid clinical assessment if they test positive for Covid). We hope this means that 2022 will see a return to more normal patterns of living for so many people who have Down's syndrome who have had to cope with so many changes and restrictions over the last two years.

Other highlights:

- A review of the Accessible Information Standard across public bodies, making sure people who have Down's syndrome get relevant information in Easy Read format.
- A review of general vaccine uptake in the UK (not just Covid vaccines, but all relevant immunisations).
- A consultation on how young adults who have a learning disability can

access funds held in a Child Trust Fund, without the need to apply to the Court of Protection.

- Social work interventions for adults who have complex needs.
- Health Assessments for Department of Work and Pensions benefit claims – this included our Welfare Benefits Advisor, Helen Wild, appearing before a House of Commons Committee to give evidence.
- A response to a consultation on the Government's Health and Disability Green paper.

We look forward to a year where we can continue to engage with key officials and make sure we can share the lived experience of people who have Down's syndrome, so that decisions which affect them and their families take account of their needs.

Listen Include Respect guidelines

I am Harry Roche, my role is Inclusion Support Officer at Inclusion International. I am seconded from Mencap which is a UK charity. I am from the United Kingdom.

The *Listen Include Respect* programme is led by Inclusion International and Down Syndrome International. We work together to create global guidelines for organisations on Inclusive Participation. We want to make sure that people with intellectual disabilities are included and are taking part in the activities and decision making of organisations. Our goal is to use the knowledge and experience from our members to create useful guidelines for organisations. We will also create training to support our members and stakeholders to put the guidelines into place.

Taking part and being included is important to me because I can be involved in the decision making with my organisation and can have a say in the decisions that may affect me and other people with an intellectual disability. It's really important to remind organisations to include people with intellectual disabilities in their work.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) says we have the right to take part in the community and make decisions, we have the right to have a job and have the right to participate and to have access to information BUT people with intellectual disabilities are still one of the most excluded groups of people. Our rights are not always respected due to how people in society think about people with intellectual disabilities. That's why organisations must understand how to support us to be included and let us take part in decision making.

Some of the barriers that people with intellectual disabilities are facing are being left behind, no accessible information, lack of support, barriers to employment, meetings not being inclusive, not enough time being given. This means that organisations are not allowing us to have our



Harry and the Listen Include Respect team

voice heard. Unfortunately, there are no international standards or guidelines for making sure people with intellectual disabilities can participate and that's why Listen Include Respect has been invented.

We have spoken to our members and heard about the barriers to being included and the solutions they know about. We have collected the good practices and written the first draft. In 2021 we sent the draft to 10 self-advocacy groups and 10 experts who gave us feedback. Now we are working on an accessible website to put the guidelines onto so it is easy to access and share with organisations. In 2021 we also did lots of testing to make sure the advice we are giving works well.

Listen Include Respect guidelines will be useful for organisations but also for people with intellectual disabilities. The guidelines will support people with intellectual disabilities to speak up and ask for their rights to accessibility and inclusion to be respected. For example, while taking part in meetings in their organisations, they will be given time, listened to, and treated with respect as individuals. We want these guidelines to break down the barriers. People in society think we cannot make decisions or take part. This is wrong! We do not get the support we need to make decisions or take part. When we do get support we have a lot to contribute.

I personally want to see really big changes on how people with intellectual

disabilities are included in decision making and in the workplace. There needs to be international standards to make sure people with intellectual disabilities can participate. There are so many barriers due to people thinking we cannot take part in society so we need to fight to encourage people to think we can contribute in our communities.



Harry's top tips for how organisations include people with intellectual disabilities

- Include people with intellectual disabilities in decision making from the start
- Make reasonable adjustments and prepare in advance
- Make easy read or plain language information
- Do not use jargon or acronyms
- Speak slowly
- Give extra time
- Support self-advocacy and pay us for our expert work

Lexie features in the BBC Good Food Magazine!

Remember Lexie, who we told you about earlier in the year who loves cooking and is writing her own cookbook? Well, the BBC Good Food Magazine saw her article on our website and contacted her about appearing in the publication. Her recipe has now been seen by the millions of people who read the magazine. What a star! We caught up with Lexie to find out more...



So Lexie, tell us all about your exciting news...

I was featured in BBC Good Food Magazine in October!

It was so exciting to be interviewed by a journalist. The article is about my love of food. I got to share a favourite recipe – I chose my cheesy breakfast flapjacks because I like savoury food best.

How did the opportunity come up?

I have always loved cooking and eating, and I have wanted to write my own cookbook for a long time. When college was closed because of the pandemic my mum and I decided to spend time on the cookbook idea. We started by asking friends and family to share their favourite recipes. They were really excited to help and I had lots of family favourite recipes to work on. I cooked each recipe and then wrote down the instructions into recipes that are easy to understand and follow. We created a website to share the recipes with everyone and we added some videos of me cooking to my LexieCooks YouTube channel. The Down's Syndrome Association shared and liked my website and YouTube channel, and someone from BBC Good Food saw and got in touch.

How does it feel seeing your recipe in a magazine read by millions of people?

I feel proud and happy that my recipe is in a magazine. But I am a bit shy so it feels a little bit embarrassing, especially when people say 'I saw you in that magazine, can I have your autograph?'

How does it feel seeing photos of yourself and reading about yourself in print?

It was really exciting to see the magazine and photos of me and my family. I was proud to share the magazine with my college friends. I got the chance to teach first year students how to make my recipe for breakfast flapjacks and I also made a big batch for my housemates. They are all very proud of me.

What are your plans and hopes for the future?

I want to sign my autograph in my own cookbook! I want my own café filled with music, family, and friends. The café will serve toasties, nachos, and of course my favourite spaghetti bolognese.

How is your book coming along?

I have been given lots of recipes from family and friends. I am using my website lexiecooks.com to put the recipes online for everyone to enjoy. I am writing my cookbook with help from my mum when I am at home from college in the holidays and we hope to be able to publish it so everyone can enjoy it and learn how to cook. So that cooking can be a fully inclusive activity, whatever challenges you might have.

What do you hope this exposure will mean for you?

I would love my own TV cooking show and my little sister Bertie can help me because she's a great cook

too! I enjoy making videos of my recipes. You can see them on my YouTube channel – LexieCooks. I hope a publisher or a programme maker will see my cooking and help me to write my book or have a TV show.

What would you say to other budding cooks who have Down's syndrome?

You are amazing. You can go for it. Don't say no! Have a go!

Try making Malcolm's Best Ever Carbonara on my website. It is so delicious, rich and creamy and easy to make.

Apart from cooking, what else do you like getting up to?

I love cooking, baking, listening to music, going to the gym, and spending time with my family and friends. I love watching Bake Off! and Strictly Come Dancing.



A huge congratulations to Lexie from everyone at the DSA.

Kirsty's VIP trip to London

Kirsty wrote to us about a very exciting trip she and her family had to London. Here's what she said:

My family and I had a fantastic weekend in London. Thanks to Becki Bateson, the DSA's WorkFit Employment Development Officer for nominating us for this event that was organised by the Sporting Bears charity and the Hilton Metropole.

We were treated like 'royalty' when we got escorted in our own Rolls Royce to have a private viewing of the crown jewels in the Tower of London.

We were one of 10 families driven through London, escorted by seven police escorts on motorbikes and a police car. Our driver Jim and guide Hugh, looked after us so well.

Crowds of people looked at us in amazement wondering who we were as the traffic was stopped for us - they shouted out 'Are you royalty?' I said 'Yes!' I felt like a princess, especially while I did my royal wave.

At the Tower, the staff were so kind and showed us around. It was only us that got to wander around at our leisure. My sister Melissa was also very excited and we both got to sit on the police bikes. We also took many photos with everyone including the Beefeaters and the guards at the Tower.



It was one of the best days of our lives especially after the difficult year we have had. Thank you everyone for making this day special.

British Down Syndrome Swimming Championships 2022

Down Syndrome Swimming Great Britain (DSS-GB) is proud to host the Championships on Saturday 19 and Sunday 20 November 2022 at K2 in Crawley.

Swimmers with Down's syndrome from all over Great Britain are invited to attend, supported by their families and friends.

DSS-GB is a volunteer led charity, which enables children, young adults and adults with T21 or Mosaic Down's syndrome to reach their potential as elite swimmers, giving them the opportunity to compete at national and international level.

They are the recognised national swimming organisation for Great Britain for UKSA and the Down Syndrome International Swimming Organisation.

Please visit the DSS-GB website for further information or to register your interest: dss-gb.org/ or email: britishdsswimmingchamps@gmail.com

A Message from Tommy Jessop

The Down Syndrome Bill is really important to all of us.

Because all of us really should have employment, education and housing.

We are not all the same, but we all have gifts and skills. Everyone has a gift, we just have to dig it out of them.

My dream for all people with Down's syndrome is to believe in themselves, have dreams, discover their gifts, become the people we CAN be, show

what we truly are capable of, and give back to others.

People with Down's syndrome now have a voice to say what we want in life.

We need people to listen to us.

We need people to say **YOU CAN** do this, not you can't.

We need people to believe in us, to help us live healthy lives and discover our gifts so we can show what we

are truly capable of.

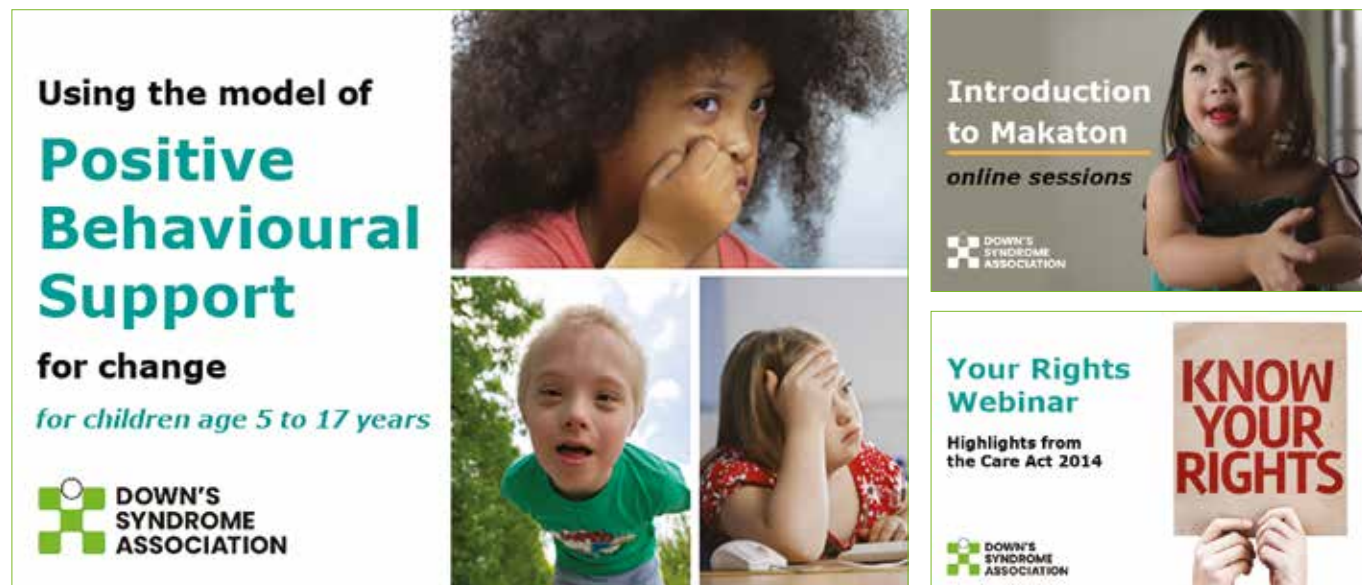
Please get this Down Syndrome Bill through Parliament so that we can start living our lives to the full and be fulfilled.

Thank you Liam Fox and Fionn, Freddie, Max, Bethany and everyone on the National Down Syndrome Policy Group so much for all your very hard work so far.

Love From Tommy

Training and Support

Over the last few months the DSA has had a very busy online training and support schedule. Here is an update on a selection of our training courses and support meetings.



The *Tell it Right* webinar for maternity services and universities continues to be a very valued session. This webinar is for all student and health professionals working in fetal medicine, maternity and neonatal services including midwives, neonatal nurses, sonographers and health visitors. It provides information on how best to support expectant parents through the screening process and how to impart information to parents and families, following a pre/post-natal diagnosis of Down's syndrome.

We have welcomed lots of new babies to our *Pregnancy and Baby* sessions, and also families who are expecting their babies who have found the sessions very helpful in preparing to welcome their new arrival. This series of four, free online meetings offers support for parents of babies up to 18 months of age and expectant parents.

We are now offering an *Introduction to Makaton* as free online sessions to give parents an opportunity to find out more about the background to Makaton, how we communicate and signing and symbols. You will also learn how to use signs at home in practical

ways with your child. At the end of the course participants will be able to sign sentences and sign nursery rhymes. The free course is made up of two sessions, each lasting an hour. Places are restricted to new parents.

Using the Model of Positive Behaviour Support for Change, Supporting Early Development, Early Years and Primary Education have been very well attended and we have had many interesting questions from school staff and parents who have accessed the training.

The *Puberty and Adolescence* session was also very popular. Parents, carers and practitioners supporting young people who have Down's syndrome attended the training session which covered body changes, hormones, privacy, boundaries, and consent. They also looked at accessible resources to support understanding around growing up.

We hold a webinar about the full range of *Housing Options* for adults who have Down's syndrome where Christopher Watson, DSA Specialist Adviser, explains the pros and cons

of common types of accommodation and discusses with parents how a person's support needs may influence their choice. Christopher also provides information at webinars on *Personal Budgets and Self-Directed Support* and *Your Rights – Highlights from the Care Act 2014*. The sessions have been well received by the parents that have attended.

Our range of free support meetings for parent carers/family members continue to receive excellent feedback. They include *Well-Being Wednesdays*, *Sharing Positive Support Online* and *Meetings for Parent/Family Carers Supporting Children and Adults who have Complex Needs including Autism Spectrum Condition*.

You can look for any of our training and support sessions and book online on our website downs-syndrome.org.uk/ourwork/services-projects/training/

We look forward to seeing you at any of our future training and support events.

What is the Our Voice team?

The Down's Syndrome Association have a team of people with Down's syndrome. Team members meet twice a week with DSA information officers. The group work as part of the DSA.

Our Voice supports the DSA with making new resources, quality checking our information and co-producing training. Group members work on self-advocacy activities and campaigns.

Why do members take part in 'Our Voice'?

Isla - I like taking part in Our Voice as it helps people being included. Welcomes new staff to the DSA. I like the T-shirt. Doing topics each week. I like doing interviews. I like taking part in DSA as it helps people with disabilities.

Lindsay - Our Voice is welcoming and I have made a lot of new friends. Made lots of videos. Generally I just love coming to the sessions and helping when I can. I can speak clearly and help out with some of the work Our Voice is doing.

Harshi - I like to talk about different things. We do lots of talking in Our Voice. We do talk about different things and do lots of activities in our sessions. I like doing discos and cooking videos. I like meeting my friends online.

Brogan - Our Voice is incredible and actually inclusive.

Andy - I think Our Voice means when people want to speak out. Using our mouths really. Taking part and make part of a team. Small groups going into different rooms and talk about stuff like school.

Sean - It's work, I like doing work with Our Voice.

Bethan - I like being together, staying connected with each other. Being part of the group.

I like doing different topics, one of the topics that I liked talking about was school. I enjoyed taking part in the focus groups.

Projects the Our Voice team are currently working on in the first quarter of this year:

- There is a team of six people working on a project with the NHS
- Completing three accessible videos for the website
- Sharing our thoughts on social media cards every week
- Working with Down Syndrome International to develop training around self-advocacy
- There are new members joining each of the weekly check-ins
- Developing and delivering training with DSA information officers
- Making a new resource about wellbeing for people who have Down's syndrome
- Working on a contribution for World Down's Syndrome Day. The theme this year is "inclusion means..."

The group have been discussing ideas for what they would like to create for WDSD and began discussions around inclusion, here are some of their thoughts below.

Elsa - we want to tell the doctors that we have rights and respect and trust them to treat us. To treat the poorly or some young people with Down's syndrome or mental health.

James - I think people need to learn to accommodate with other people. People need to learn to talk to other people who are around them.

Katherine - I just want to be in a safe and friendly environment. I want to have the opportunities.

Sam - working all together as a team – teamwork.

Joe - Freedom, this can mean anything! Support. Feeling empowered.

Catherine - Teamwork, freedom, feedback, support and feel safe.

The DSA is extremely grateful for the time the team has dedicated to improving the lives of other people who have Down's syndrome.



'Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.'

Margaret Mead

Meet Jesal, aged 5

By Priya Pancholi



A happy, caring and loving little boy, full of character, stubborn and knows his own mind!

Jesal has an older brother (11) and sister (7) who love him dearly. They are part of his everyday routine and he very much enjoys playing with them and wants to be included in everything they do. His siblings have helped with his development and understanding.

Jesal was born with a hole in his heart, but thankfully he has been discharged from cardiology and is doing well. From a young age, Jesal has suffered from many occasions of pneumonia, his latest admission was in January 2020 with lung failure and he spent over a week in hospital recovering. Thankfully, with the efforts of the NHS he made a speedy recovery and is a fit young boy. This can be very worrying and stories like this can make parents anxious about their child's long-term health. However, I can say this; that it does get better and as Jesal grows, he becomes stronger and more able to fight the bugs he catches.

Jesal has low muscle tone and is on the more severe end. He didn't walk until he was three years old, which is relatively late. Low muscle tone can be very common in Down's syndrome, and with Jesal this affected his ability to crawl, stand and walk from an early age. We found a private physiotherapist who helped him walk and achieve milestones. This included jumping, running, getting up without hand support and climbing stairs. I would

fully recommend physiotherapy for children with low muscle tone.

Jesal started wearing glasses from two years old and shortly after, he was given a BAH1 hearing aid. Both aids have helped him focus more, supporting his language and visual ability. He even asks to put his glasses on, especially when he is using the iPad or watching TV! He isn't so keen on his hearing aid, but we continue to persevere.

Jesal turned five in January and currently attends a specialist school on a full-time basis. He attends a reception class and is learning the (EYFS) Early Years Foundation Stage curriculum. His learning is managed through play, one to one adult supervision and group task settings. He has settled in to school really well and is very much enjoying the routine. Jesal has been learning to count using objects and recognise numbers. He's participated in science experiments and creative play. He has weekly PE and swimming sessions to help support his balance and strengthen muscle. Jesal attended a mainstream nursery from the age of one and I feel this has really helped with his social skills and he will easily make friends. He is caring and considerate of others, and mostly happy but can have tantrums and become frustrated at any point, even when his surroundings are calm.

The frustration can be due to lack of communication as he is not fully vocal. Jesal uses minimal words and is making two-word sentences, but communicating through Makaton has been a huge help for him and us all. He loves to watch Mr Tumble episodes (at least three times a day!) and has learnt so many Makaton signs and has even taught us some! Me and my husband have also attended a Makaton session which was very useful.

School has helped Jesal with mark making, painting and sorting type puzzles with supervision. He loves singing and dancing and playing with instruments and finds this fun! He also enjoys reading, playing with balls (he has a cricket bowler throw!) and playing with cars. Noisy toys help keep him occupied and he has been like this from a very young age.

With me and my husband both working full time, the school routine helps significantly. With the flexible working and family support, we can manage his needs and routine well. Every day is different and we are constantly learning how to adapt with Jesal's needs, but we get through, and if it's a bad day, the next day will be better!

I also have an Instagram page providing regular updates on Jesal and his progress and what he's been up to! You can follow me on [@mum_to_jesal](https://www.instagram.com/mum_to_jesal)

DSA Helpline: Health Queries with Dr Liz Herrieven

The Down Syndrome Medical Interest Group (DSMIG) work to provide information to health professionals to help them provide health care to people who have Down's syndrome. The Group is also very proud to work with the DSA on all sorts of health-related topics. One of the things we do is help the DSA information team to answer questions that families and carers ask via the DSA Helpline.

Here's some of the topics we've been contacted about in the past year.

Tests, Appointments and Hospital Stays

We are often asked about whether certain tests are appropriate for people who have Down's syndrome, whether they need specialist input for particular symptoms and how to manage a hospital visit or stay.

The first thing to remember is that people who have Down's syndrome can get other illnesses too, and that doctors and other health care professionals should, in the vast majority of cases, do the same tests and give the same treatments that they would for anyone else. Sometimes, particularly when those tests might be distressing, then things need to be done in a slightly different way. For example, for an endoscopy (a camera test, looking at the gullet, stomach or bowel), a person who has Down's syndrome might find this particularly difficult to manage and so may need to have the test under sedation or a general anaesthetic. The same might be true for an MRI scan, which can feel noisy and claustrophobic for anyone, let alone someone with sensory processing issues or a learning disability. For blood tests, different people will need different levels of support. Some blood tests can be done by a finger prick, avoiding the need to find a vein, which can be helpful. If 'proper' blood tests are to be taken, it's worth asking if the person is due to have any more blood tests in the near future and, if so, whether they can all be done at the same time. If the person is having a general anaesthetic for something like a scan, endoscopy or dental treatment, it is likely that the blood could be taken at the same time if the difficulties are explained to

the medical team. The anaesthetic and endoscopy team for example, wouldn't usually be involved in taking blood for most patients so might not be aware of this.

Numbing creams can be really useful, although some people get quite distressed with the cream on, waiting for it to work. Another option is 'cold spray', where a very cold spray is put on the skin just before the needle is inserted. Preparation is really important, both for the person having their blood taken, and for the team doing the taking! The best chance of success is when everyone is calm and when the person taking the blood has a chance to look for a good vein and get into a good position. It can help to talk about what will happen in advance, including showing photos or pictures. For some people who have Down's syndrome, distraction can be useful, such as watching a favourite show on a tablet or looking at a favourite book. For others, particularly those who have had lots of hospital visits, distraction has no chance of working. Often parents or carers will know what will work best for their loved one – don't be afraid to tell the medical team if so. Sometimes blood tests can be performed away from the hospital or medical centre, such as in the person's home or school. Being in a familiar place with familiar things around can help. If you are very lucky, a play specialist or learning disability nurse can help with preparing the person and getting them through a procedure.

When it comes to treatments, often the right treatment for someone who has Down's syndrome is the same treatment that anyone else would receive. Again, some things might need to be tackled in a different way, such as drips, oxygen masks etc, as described above for blood tests.

Adults who have Down's syndrome should be involved in making decisions about their own care. Any information should be in a format that is easy to understand and they should have the opportunity to ask questions if they wish. For adults who are not able to make a particular decision (and this can vary with the decision, the level of urgency, how the person is doing in themselves etc), then any decisions made by the medical team must be in the person's best interests. Often this means going ahead with a treatment but sometimes, particularly for procedures which are very invasive or uncomfortable, this may mean choosing a different option or leaving well alone. The medical team do not make these decisions lightly and must take into consideration how this will affect the person, along with any measures that could be taken as an alternative. They should explain why and how they have come to their decision, and should listen to any information offered by those who know the person best. Again, a learning disability nurse can help to offer suggestions about how to enable people with learning disabilities to cope in different situations.

Constipation

Constipation is certainly more common in people who have Down's syndrome and we get plenty of queries about this through the helpline.

In many cases, constipation can be managed by diet and/or laxative medications. Most often, this is a type of medication called a macrogol, which comes in powder form, mixed in water (eg. Movicol). This medication helps to draw water into the stool to keep it soft, making it easier to pass. Therefore, it is also really important to drink plenty of fluids, too. Different

people need different doses and it can sometimes take a while to get this right. Diet is important too of course, with wholegrain foods and vegetables high in fibre being a great help. It's not all about medication and diet though – getting used to going to the toilet regularly and addressing any anxiety or sensory issues also helps.

Sometimes, constipation can be caused by other medical conditions, such as coeliac disease, underactive thyroid or Hirschsprung's disease. Again, Hirschsprung's disease is a little more common in children with Down syndrome. The nerves supplying the bowel and keeping stool moving along it don't form properly, so the bowel doesn't function as it should and the child becomes very constipated. Often this constipation starts straight after birth, with a delay in passing the sticky black stool called meconium. Hirschsprung's disease is confirmed by a biopsy (sample) of the bowel tissue and is treated by Botox injections or removing the affected part of the bowel.

Vaccination

This is a really common area of concern. There is a useful guide for parents in the Down's syndrome insert for your red book (PCHR) Personal Child Health Record. Babies and children who have Down's syndrome generally follow the same vaccination schedule as all other children. In addition to this, they should have their flu vaccination from six months of age, as influenza can be a serious illness in those with a weaker immune system (such as people with Down's syndrome), and can also lead to complications such as pneumonia. For those under two years old, this needs to be given in the inactivated, injection form. From two years old, children can have the live attenuated vaccine in nasal spray form. Attenuated means that although the virus is 'live', it has been altered so it does not cause the flu, but still causes the immune system to mount a response. Not only does the spray avoid the use of needles, but studies show that this is the most effective form of vaccination for children, working better than the injectable form against many variants of influenza. Some children can't have the live attenuated vaccine and should have the injection instead. This includes those on high doses of steroids or

those receiving chemotherapy, those with severe asthma and those with an egg allergy. The spray is perfectly safe for the vast majority of children who have Down's syndrome. Adults are generally given the injected version of the flu vaccine and all adults with Down syndrome should continue to receive the vaccination every year.

Side effects of the flu vaccine include a runny nose, tiredness and sometimes a headache. Those getting the flu vaccine for the first time should be given two doses, four weeks apart (injection or spray).

Pneumococcal vaccination is routinely given to all babies in the UK as part of the first year injections. This vaccine helps to prevent infections caused by some of the commonest strains of the pneumococcus bacteria, which can lead to some types of pneumonia, other respiratory infections, meningitis and sepsis. An additional pneumococcal vaccination (Pneumovax two) is available and offers protection against more strains of the pneumococcus bacteria and is recommended for all those who have Down's syndrome after the age of two (it's not too late to get it as an older child or even as an adult if you've missed out).

Skin Problems

We are often asked about rashes. Some rashes can be a sign of serious underlying illness – for instance a rash that looks like tiny pin prick bruises that doesn't blanch (disappear or go pale) when you roll a glass tumbler over it. If you are unsure or if the person is unwell, you should seek medical help.

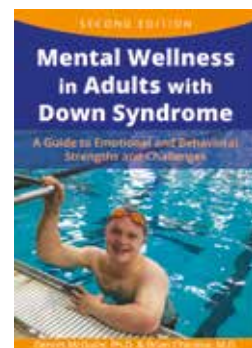
More often we are asked about a rash that has been present for ages and isn't getting any better. These can be the same sort of rashes that are common in the general population eg: eczema or psoriasis, but some types of skin problems are much more common in those who have Down's syndrome.

Folliculitis is a common rash in people who have Down's syndrome. It is a red, raised rash, sometimes itchy, caused by inflammation of the hair follicles. It's often seen on the back, arms or legs and may be present for many months. Antibiotics are often tried, but don't always work. If they are used, they sometimes need to be used for many weeks. Keeping the skin clean and dry can help. Regular showers and baths,

making sure the skin is completely dry before dressing, can be useful, along with avoiding clothing that rubs or is tight, and avoiding getting sweaty (or cleaning the skin and changing clothing if you do get sweaty). Weight loss can also help, if the person is overweight.

Sometimes the problem is one of boils, or abscesses, under the skin. These are again more common in people who have Down's syndrome and can be painful and difficult to treat. The treatment is often similar to that of folliculitis, as above. Sometimes the boils need to be drained or removed surgically. Depending on the boil and on the person, this may involve local anaesthetic injections, sedation or even general anaesthetic. With recurrent boils, it would be wise to check for other health conditions which can also make the situation worse, such as diabetes or an iron deficiency.

As you can see, the Helpline receives lots of different queries about health, and the DSA and DSMIG teams are always happy to help wherever we can. Do get in touch if you have any questions for us.



Mental Wellness in Adults with Down's Syndrome

by Dennis McGuire and Brian Chicoine

(Woodbine House, 2nd Edition 2021)

As this edition of the Journal carries reviews of our emotional well-being resources, we thought it would be helpful to let you know that the long awaited second edition of Mental Wellness is now available.

Healthcare for people who have Down's Syndrome and Complex Needs

Introduction

People who have Down's syndrome should expect the same quality of healthcare as anyone in the population. If a person who has Down's syndrome and/or their supporter visits a health professional with their worries or concerns, they should always expect what they say to be taken seriously. In accordance with the Equality Act 2010, there is a legal duty to make reasonable adjustments to services to make sure people who have disabilities face as few barriers to getting good healthcare as possible.

Although much has changed for the better in the provision of healthcare in the last few decades, we know that people who have Down's syndrome still experience poorer health outcomes than are seen in the general population. Families tell us that accessing timely and appropriate healthcare for people who have complex needs and/or Autism can sometimes bring with it certain challenges, that are not necessarily faced by other people who have Down's syndrome.

This issue has been a topic of discussion at our parent/carer complex needs meeting. It has prompted us to develop and disseminate a questionnaire to collect information about personal experiences of accessing health provision. A call for participants was made via our newsletter and social media platforms. Following the call out, we emailed questionnaires to 14 voluntary participants over the period July to September 2021 of which 8 were returned. The information in this article also includes experiences shared by the attendees at the July 2021 complex needs meeting.

We asked eight questions including what works in healthcare settings, any measures that have been put in place to ensure access, what preparation is needed, if any, helpful resources, key issues and examples of good practice.

The total number of parents who shared information either via

questionnaire or in the meeting is 14 including 13 mothers and one sister. The ages of the people who have Down's syndrome ranged from 3-66 years old, with half in the age bracket 19-25. This included one person who has Mosaic Down's syndrome and complex health needs. As the participants were self-selecting, the term complex needs covered a range of conditions and was open to interpretation by the parent/carer.

What we learned

Several themes emerged with regards to what works well in healthcare settings. These included the environment, communication, preparation and incentives.

The need for a calm, quiet, unhurried environment was a recurring theme throughout. What works well is appointments happening at a set time to avoid long waits and therefore the need to sit in noisy, busy spaces. One parent mentioned that some of the measures in place during the pandemic had been very helpful, including waiting in the car and then going straight into the appointment and avoiding the waiting area completely.

Also helpful was seeing professionals who know the person and who are friendly and able to explain things clearly to all parties. Some words mentioned by respondents with regards to what worked well were calm, not rushed, understanding and gentle.

In acute settings, the involvement of professionals who have knowledge of supporting people, such as specialist teams/learning disability nurses, was reported to make a big difference. This could be to act as an advocate or just to accompany and offer support.

Several parents mentioned the importance of preparing in advance and in some cases using rewards as well as lots of praise throughout an appointment.

Some of the strategies included using photographs, a visual schedule or a social story to help their son or daughter understand what is going to happen and who they are going to see. One parent mentioned how they will prepare for several days prior to an appointment, and another talked about role playing the appointment in advance as preparation. One mother said that when having an appointment in a new environment, it helps to have several visits in advance. Also mentioned was the importance of packing things that can be used to relax/occupy/distract/reward during waiting time or in the appointment. For one person, part of their preparation involves contacting a learning disability nurse in advance who will then accompany them.

One person talked about a recent event which involved her and her son waiting for several hours in A&E to be seen. During a subsequent visit they were allocated a quiet separate space which made a huge difference to the experience. A suggestion made by one parent was to have a second person in the room to occupy her daughter. On a previous occasion when this happened, it made the appointment a more pleasant experience and enabled all the relevant information to be discussed.

With regards to specific measures that had been put in place, the support of specialist learning disability services, in particular learning disability nurses, were mentioned repeatedly. Two parents referred to the annual health checks by the GP and one parent appreciated that if she rang the GP they would always offer the option of a face-to-face appointment.

We asked whether people had a hospital passport and received a wide variety of responses. One person had not heard of them, several said their son/daughter had one but it needed updating. A few people were in the process of developing one. Two people commented that although their child

had a passport, they did not think the professionals looked at it. One person had developed their own short information profile in case of Covid.

We also asked what key issues health professionals need to be aware of with regards to access, and a number of themes emerged around personal qualities, appointment times, environment and communication. Professionals showing empathy, taking their time and not rushing were repeated themes. The option of longer appointment times and additional visits, as preparation, were also highlighted. On a practical note, having appointments that were local was seen as important for one parent.

The need for good communication and information sharing with parents and between professionals was mentioned. This included both addressing the person who has Down's syndrome directly, as well as talking to parents and recognising their expertise.

The final question around access invited parents and carers to give us examples of good practice that stood out for them. Below is a summary of the responses:

Gold Standards

Relationships are very important, including seeing a health professional who knows the person whenever possible.

Preparation for the appointment by the health professional.

A calm and empathetic approach by the health professional.

Good communication between professionals.

Support from learning disability specialist teams or a learning disability nurse.

A flexible approach during COVID.

Finally, we asked whether people had used any of our easy read resources and whether there are any resources that would be helpful for us to develop.

One person told us they had found our resources particularly useful. Another had used them when their child was younger but not recently. Several had not used them at all.

With regards to resources that we could develop, suggestions included Down's syndrome and Autism, specific health conditions and a guide for professionals on good practice for health appointments. One person felt that a bank of photos and symbols for health care settings would be helpful.

Challenges

Amongst the examples of what worked, we received information on what hadn't worked for the person who had Down's syndrome in accessing healthcare. Three things that came up repeatedly were waiting a long time to be seen, noisy/busy waiting areas and feeling rushed. One example provided was of a child and mum waiting nearly 5 hours in A&E with no allocated quiet space.

Communication was another issue that came up in different ways. This included examples of professionals not communicating with either the child or in another case the parent. Also, professionals displaying a lack of empathy, in some cases talking negatively about the person in front of them or making assumptions and referring to historical negative information. One parent raised how a health professional had a lack of awareness about mental capacity and did not make any effort to talk to their adult child and ask their views.

Conclusion

The last couple of years have resulted in changes to accessing healthcare, which in some regards have facilitated the conditions which many of our

respondents referred to. The physical spaces have been quieter, there has been less waiting and more time allocated for appointments or the alternative of an online appointment has been an option.

As services begin reverting to a pre-Covid normality, healthcare environments may also be returning to a culture of overbooking appointments, shorter times, stressed professionals and busy waiting rooms. These were all identified by parent/carers as barriers to equitable and timely healthcare.

The support available to families is variable depending on geographical location. Access to specialist teams/learning disability nurses was highlighted throughout the questionnaire as making a real difference, but there is an acknowledgment that these services are not always an option.

Parents also talked about the degree of preparation/pre-emptive measures they need to put in place to ensure that appointments work. Developing Health Action Plans/Hospital passports in themselves are not useful unless they are used and taken notice of and only then can they be of enormous benefit.

The commonality of what works

- Connection
- Appropriate communication
- Calm environment
- Time and space
- Specialist help when needed
- Preparation

We would like to thank everyone who contributed to this article and we plan to use this very useful information to put together some guidelines which we will share with DSMIG.

Research Update

Ongoing research support

We continue to support postgraduate research studies by advertising for study participants via our website and social media. We write letters of support for researchers who are applying for funding, and we act as research partners which may involve attending meetings about the development and progress of studies. An example of the latter is our involvement with the Oxford University study looking at fractures in people who have intellectual disabilities.

We are always happy to consider supporting studies where there may be potential benefits to people who have Down's syndrome and their families. As part of our vetting process, we ask for evidence of ethics approval and, if a study involves the recruitment of people who have Down's syndrome, the provision of accessible materials.

The Our Voice Group play a vital part in supporting research studies. Our Voice has helped with a University of Manchester and Health Education England study looking at how to improve hearing services for people with learning disabilities.

One of the researchers on the study writes:

'We recently held a focus group with members of the 'Our Voice' group who have accessed hearing services. It was fantastic to hear the group's perspectives on the care they have received and their ideas for how services can be improved. It is vital to hear the voices of people with learning disabilities in research, especially around the services they receive. Thanks to the 'Our Voice' team for enabling us to do this.'

Between 2019 and 2020, we supported 27 research projects.

Here is a selection of Down's syndrome specific studies that we are currently supporting:

Speech fluency in people who have Down's syndrome (Wayne State University, USA)

This study aims to get a better understanding of the speech traits common in people who have Down's syndrome, and particularly those that affect speech fluency (ie: flow or ease of talking).

Evaluating the quality of Education, Health and Care Plan (EHCP) outcomes for primary school students who have Down's syndrome in England (University of Oslo, Norway)

This study involves examining EHCPs in order to evaluate the quality of their outcomes and provide further evidence of the importance of high-quality outcomes in regard to student success.

Eye care in people who have Down's syndrome: understanding the provision and the impact of Covid-19 (Aston University, UK)

The study looks at the experiences of adults when they receive eye care. The research team hope their findings will lead to improved and more accessible eye care services for people who have Down's syndrome.

The lived experiences of new mothers accessing feeding support services for infants who have Down's syndrome throughout the Covid-19 pandemic (University of Herts, UK)

The aim of this study is to find out how the feeding support services available to mothers of infants who have Down's syndrome have changed because of lockdown, how these changes to services have impacted the support they have been able to access, and what their experience has been like during this time.

Language in adults and young people who have Down's syndrome (UCL, UK)

People who have Down's syndrome may show changes to their cognitive skills as they get older and the research team are interested in finding out more about how language is affected by these changes. They hope that learning about the relationship between age, cognition and language will help them to develop better support for people

who have Down's syndrome across their adult life.

Exploring relative strengths in people who have Down's syndrome: spatial thinking and its role in maths (University of Surrey, UK)

The main aim of this study is to investigate spatial abilities and mathematics in people who have Down's syndrome. This includes finding out about relative strengths and challenges in different types of spatial tasks, examining the development of spatial abilities, and finding out whether spatial abilities predict maths outcomes in people who have Down's syndrome.

Social cognitive strengths and difficulties in Down's syndrome (University of Surrey, UK)

This study looks at how children and young people who have genetic syndromes process and understand social information. It aims to identify whether there are social processing differences characteristic of specific syndromes, and how these may relate to the presentation of autism traits.

Survey on the impact of the Covid-19 pandemic on children under 11 years old who have Down's syndrome (UCL, UK)

Professor Lakhanpaul and the team at UCL have teamed up with the Down's Syndrome Association and Trisomy 21 Research Society to develop a survey to understand the impact that the pandemic has had on children under the age of 11 who have Down's syndrome.

Investigating eye shape and its effect on focusing in Down's syndrome (Aston University, UK)

Many people who have Down's syndrome need to wear glasses to help see things far away and up close. Dr Vinuela-Navarro would like to know why this is the case.

This study aims to further our understanding of the origin of poor near focusing in people who have Down's syndrome, by studying the shape and size of different eye structures involved in near focusing in this population.

DSA Initiatives

The DSA is funding a brand-new research project into the cause, recognition, and possible treatment of Unexplained Early Regression.

The team at the Cambridge Intellectual and Developmental Disabilities Research Group will start the research in Spring 2022, and we will be calling for participants through our usual channels.

If you know someone who has Down's syndrome who is experiencing,

or has recovered from this type of regression, we would be pleased to hear from you.

Further information about regression and the forthcoming study is available here:

downs-syndrome.org.uk/our-work/services-projects/researchsupport/

Why is research important?

Research is important in that it may provide evidence and information with which to effect positive change in the lives of people who have Down's syndrome.

Please take a look at the studies we are currently supporting and take part if appropriate. Your involvement may help people who have Down's syndrome in the future.

downs-syndrome.org.uk/our-work/services-projects/research-support/

An update from the WorkFit team

We have mainly been delivering our WorkFit programme online since the pandemic, and are delighted to be continuing its success of developing employment opportunities for our members who have Down's syndrome.

We have seen a real surge in interest from employers in the last eight months, and we celebrated a record number of people starting new jobs in November 2021. While there is still some understandable uncertainty in some industry sectors, we are hugely optimistic about the future.

We also wanted to share some of the great things that have taken place in the last few months...

WorkFit were invited to deliver a keynote speech at this year's World Down Syndrome Congress hosted by the Emirates Down Syndrome Association in Dubai. WorkFit candidates Thomas and Tommy from GXO Logistics, along with their work colleagues and our WorkFit Employment Development Manager, spoke online about their work and the theme for the congress, which was 'unlocking hidden potential' - something that we do every day at WorkFit. It was an uplifting presentation which you can watch online at:

bit.ly/WorkFitWDSCPresentation



We were thrilled that two WorkFit members won awards (one candidate and one employer) at the British Association of Supported Employment Conference 2021. It was wonderful to see Angus Addenbrooke win the Highly Commended Award in the category of the David Grainger Award for his role as Office Administrator at The Developer Society. We were also delighted that The Spicery was recognised with a Highly Commended in the category of Best Employer Practice, for their support of employee Rhys, who collected the award on behalf of his colleagues. Both Angus and Rhys gave wonderful speeches at the conference dinner when they collected the awards, and later danced the night away with the WorkFit team.

In September, Roy Perrett joined forces with the Swindon Down's Syndrome Group as a WorkFit Liaison Officer to help more people who have Down's syndrome in the Wiltshire area find employment. Roy has first-hand

knowledge of the WorkFit programme following his work with Luke, who joined Roy's Control Room team at Wiltshire Police in July 2016 and has been there ever since.



Finally, if all that were not enough, our WorkFit Employment Development Manager, Alison Thwaite met the

Minister for Disabled People, Work and Health, Chloe Smith MP, at the Hilton London Metropole to tell her about WorkFit and introduce her to three WorkFit candidates employed there. The minister spoke to Sam, Brogan and Shomari about the permanent, paid jobs they secured at the hotel through the WorkFit employment programme, and they demonstrated their work and told her what their roles mean to them. Watch this video from BBC News of the visit: bit.ly/MinisterVisitHiltonMetropole

To see more of our candidates in their jobs and to hear from them and their employers, our YouTube channel can be found at: bit.ly/MinisterVisitHiltonMetropole

To keep up to date with the latest WorkFit news, follow us on Twitter: twitter.com/DSWorkFit

Getting 2022 Off to A Swimming Start!

Many of us have really missed being able to go to our local pool for a swim during the lockdowns. Swimming is an important life skill, is really good for us and is lots of fun too. Here swimmers Kathryn and Mark from Down Syndrome Swimming GB (DSS-GB) share what they love about swimming.

Kathryn tells us why swimming is her passion



I started swimming lessons when I was five and when I was eight, I started at Electric Eels Down's Syndrome Swim Club. I went to competitions and got faster. I moved to Reading

Cygnets disability club and Bracknell and Wokingham mainstream club, and I still swim at both. When I was 15, I was asked to join Downs Syndrome Swimming GB! When I was 16 I swam with them in Italy. I was very excited. I got an individual and relay medals. We got a European record and I was so proud to be on the podium with my teammates, GB flag round me and the national anthem playing!

I have been to Florence, Canada, Paris and Sardinia to swim for GB, and got medals at them all! This year I went to Italy but because of Covid no parents were allowed. It was just the team. I really liked that. Swimming for GB and wearing the kit is incredible. It makes me and my family so proud.

Covid meant no training or galas for a long time. I am so happy to be back in the pool and I'm looking forward to the Championships in November – it's on my birthday so even though I will be swimming I will be seeing all my GB team friends!

Swimming is my passion. I love to swim and to push myself. Improving my skills and getting better times. I like to go to galas. I like being fit and train about

four times a week. I always want to go but I don't much like to get up really early on Sundays. I have swimming books and my mum explains things to me. I have a smart watch which shows me how hard I've worked. It really helps me. Swimming has helped me be more confident, make friends, learn new things and make me feel good about myself.



Mark tells us why with hard work, anything is possible



My swimming story started when I was a baby. My parents decided for safety and fitness it was important for me and my brothers to be confident in the water. Before I could walk, I would

dash around the pool in my rubber ring and arm bands, splashing mum and dad. I had lessons with Sheila, who was a patient but firm swimming teacher and at age 11, I began with Hitchin Swimming Club. Swimming became a family affair. My brothers joined the club, my dad qualified as a swimming teacher, and mum was our biggest supporter - driving us to training and galas, being on poolside with snacks and dealing with wet towels!

In the early days, local galas weren't accessible to swimmers who didn't swim

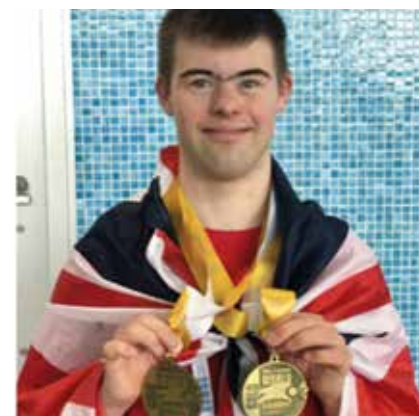
the qualifying times, so we travelled a lot to disability galas. I realised I was slower than my peers at Hitchin, but I was quick compared with other swimmers with Down's syndrome and at 13, I set my first junior world record.

I was first selected to represent Great Britain when I was 16. In 2018, I was part of the DSS-GB Team at the World Championships. I finished third overall with three gold, two silver and two bronze medals. The next year I became European Champion.

I now hold four World Records, but swimming is about much more than records and medals. Swimming has made me realise that with hard work, anything is possible. Alongside my swimming, for the last four years, I have worked full time for a local engineering company. My success in the pool has given me fitness, confidence, self-esteem and the belief

that I can do anything that I put my mind to.

Lockdown was difficult with pools closed. DSS-GB kept us all going with weekly Zoom calls with guest speakers, fitness classes, quizzes and cooking sessions. Now 25 and officially a 'Masters Swimmer', I am still training hard and looking forward to the next World Championships as well as the British Championships in November.



DSA's Accessible Emotional Well-being Resources – A Review by Our Voice

In 2020, we published a range of accessible emotional well-being resources, including a film about relaxation, a relaxation audio, and a series of Easy Read titles as below:

What Is Mindfulness?

How Am I?

Talking About Feelings

The Stress Bucket

Bullying

Changes That Can Happen in Families

Managing Anger

Well-being Top Tips

Things You Can Make or Buy

People who have Down's syndrome were consulted throughout the development process. These accessible resources sit alongside a resource for parents/carers about supporting the emotional well-being of people who have Down's syndrome. There is a parent review of the resource for supporters in this edition of the Journal.

To ensure the resources remain relevant and up to date, we asked for volunteers from Our Voice to take part in a Zoom focus group to review a selection of them. Here is what they told us:

A film about relaxation

Bethan

'I like the video because it is very useful. It helps me understand about relaxing and I find that very interesting and it's good information about yourself, health, and body. Talking about relaxation helps you keep very calm.'

Lindsay

'I liked helping with the video because it was nice to tell people what we have been doing. I liked the video. It was really helpful watching it and hearing what people thought it really helped. I liked that it was Our Voice members that had created the video, it's nice to hear their thoughts on how they're feeling.'

I think what makes it better is getting people together talking about what we are feeling.'

Harshi

'I like lots of people giving ideas and I also like having writing on the screen (subtitles) that was good.'

I think everything was good there's nothing to be improved.'

Rhys

'It was good seeing other people with Down's syndrome.'

Claire

'I like the fact the video is simple and easy to follow and straight to the point.'

The writing on the screen in between shots could have a voice over as well. I noticed that when they (the person) showed a picture, they need to share the picture on the screen so we can see it.'

Little bit of music needed.'

Alex

'It had good information. I like all of it, people on the Zoom. They could speak up a bit more.'

The Stress Bucket

Harshi

'I like the smiley face, and the pictures are very good.'

Pictures are good and writing helps

The stress bucket is lots of good ideas. Have other ideas on it. And it's simple language and it's not too long to read. I love the pictures.'

Claire

'As I was reading that, I think there are a few commas missing out.'

Rhys

'Bubbles pictures and things to make me feel stressed or things that make me feel better. Understanding it was hard I understood it better with examples.'

Alex

'Being stressed can be really hard and when you're under pressure. It can get in your head it doesn't help when you are stressed. I get a bit worried about everything, like doing things. I get a bit anxious. It comes and it goes.'

Lindsay

'The pictures are good. I didn't understand the bit about the exercise one. I think all the others made sense, yet I was confused with the running one.'

Bethan

'The pictures are good and the words and they are very useful but on that Easy Read you know you took a picture of the stress bucket, I'm thinking if instead of having a stress bucket you could put a picture down of a journal.'

Additional notes for The Stress Bucket:

Several people said we need to break some of the writing down into smaller sentences.

A number of people in the focus group said a picture on page two of people running was a bit confusing.

Relaxation Audio

Everyone had so much to say during our Zoom focus group meeting that we ran out of time to talk about the relaxation audio. So, we asked people to email us their thoughts. Here is Bethan's feedback:

'I find it very useful.'

Good clear instructions.

Good understanding about how to relax your body.

It helps to relax your muscles and to be calm.

It helps to release your inner self and your mind.'

All the resources covered here can be found on our website: downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/emotional-wellbeing/

Supporting Emotional Well-being for Parents and Supporters

by Ann Kenwright, parent

The DSA have produced a fantastic guide to help support positive emotional well-being for people who have Down's syndrome, their families and their supporters.

The suite of 12 'Supporting Emotional Well-being Resources' has been written by our expert DSA team with the help of 90 people who have Down's syndrome from all over England and Wales.

The resource is very comprehensive, covering a wide range of life experiences and different stages of life. It is packed with lots of ideas and strategies to help you prepare for and support, both yourself and your loved ones, at times when life can be a little more challenging and stressful!

Although a large document, it is surprisingly easy to navigate thanks to the clever use of hyperlinks on the contents page and throughout each section. This allows you to quickly jump to the parts you wish to look at, without endless scrolling.

The DSA team have worked really hard to make this resource as easy to use as possible. Sections are written succinctly and in plain English without jargon. Each section has a central takeaway message, outlined in a box, to grab your attention.

There is also great use of bullet points and illustrations throughout to communicate the key points easily, without you having to read through pages and pages of text.

The advice, hints, tips and strategies are clearly written, straightforward and easy to understand. There are links in every section to accessible video, audio and Easy Read resources which you can share together with your family member who has Down's syndrome.

The resource itself is divided into nine key sections. Each section is then broken down into different topics.

The first section is an introduction to the DSA's library of accessible

well-being resources. This is followed by 'The emotional well-being of parents, carers and supporters'. This addresses the importance of self-kindness and how mindfulness techniques can help us recognise and deal with both conscious and unconscious stress.

'Physical health and emotional well-being' discusses the connections between our physical, emotional and mental health. We know that our loved ones with Down's syndrome can sometimes struggle with recognising and expressing feelings of pain, discomfort, poor sleep or low mood. This chapter also explores when and how to access support.

'Learning about and recognising our emotions' deals with the complexities of emotional regulation. It has lots of ideas and resources to help us make sense of feelings and manage our own and others' emotions.

'Self esteem and self identity' explores the many positive ways we can support people to develop their own ideas, opinions, needs, wishes and dreams, and have them heard and understood. There is a particularly lovely section on how personal books and life story books can help to support self-esteem and explore identity.

'Independence, taking risks and choice' helps us to navigate the tricky balance between keeping our loved ones safe while still encouraging them to make their own choices, learn new skills, and develop their independence. There is lots of great advice on using visuals and film guides, choice boards and sorting activities to support this.

'Life stresses and strains' looks at the factors which can affect a person's well-being and development at different



stages in their life, from early childhood to adulthood. Topics covered are very wide ranging, including: teenage years, imagination and fantasy, self-talk, relationship issues, and dealing with change and loss. There is helpful advice for several different scenarios as well as lots of ideas for using visual timetables and social stories to good effect.

'Difficulties and coping strategies' is the largest chapter and deals with some of the most difficult topics including stress, anxiety, grief and bereavement. It lists the obvious, and not so obvious signs to look out for which might show when someone isn't coping so well. There are tips and strategies to both prepare and support people, and guidance around when and how to seek professional advice.

The final section is about 'Spirituality' and the important role it plays in people's emotional well-being. This section explores how spirituality can mean different things to different people, and offers ideas on how to support others in meeting their spiritual needs.

This is an absolutely brilliant resource which is very easy to use and dip into. It is jam-packed with tips, ideas, strategies and resources - an emotional well-being directory of support for families and supporters everywhere.

Supporting Emotional Wellbeing
downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/emotional-wellbeing/

Thank you to our corporate supporters

Our thanks go to all the companies who have supported the DSA in 2021. With these challenging times, the demand for our services continues to grow, so support from companies is more vital than ever before to enable us to provide help to people who have Down's syndrome, their families and carers.



Simplyhealth has supported the DSA for a number of years and in 2021, they recognised the importance of the DSA's mental well-being work. Looking after the mental health of people who have Down's syndrome, as well as their families and carers is something we consider really important. Simplyhealth generously donated £20,000 to help support our work on this, from producing Easy Read resources, to online meditation sessions and relaxation audios.

'Simplyhealth is proud to be supporting the Down's Syndrome Association with the important work they do on their mental well-being projects. We all know how hard life has been with lockdowns and the feeling of being isolated, so now more than ever this support is so needed and we applaud the work the DSA are doing in the space.'

Wendy Cummins, Community Manager, Simplyhealth.



Last year, our fantastic charity partnership with KAEFER UK & Ireland led to an amazing donation of more than £13,000 through the support of the company and fundraising by employees.

Our thanks go to all employees for their support and to Trevor Woodward, Director of Business and Strategy at KAEFER UK & Ireland who has also raised so much for the DSA through taking part in the London Marathon and our skydive in 2021.

Chris Foulkes, Chief Executive Officer of KAEFER UK & Ireland commented:

'2021 was the commencement of our long-term partnership with the DSA and we witnessed the whole of the KAEFER business really getting behind this relationship. We had individual and team contributions that delivered some fantastic results financially and personally.'

When KAEFER started this journey with the DSA, it was with our intent that we wanted to ensure that we made a difference to the lives of people with Down's syndrome and their families, it was not just about raising money, although that also helps. With the WorkFit programme, we have been able to start providing life skills opportunities for people who have Down's syndrome across

KAEFER's business within functional and operational roles. We will be working hard with the help of the DSA team to expand the WorkFit programme further across in KAEFER in 2022.

I have also witnessed the positive effect on our employees' mental wellbeing by helping others. We are very privileged that we are in positions that we can support and help others and we can never lose sight of how privileged we are.

2022 will be another fantastic year for KAEFER and the DSA, and I'm personally super excited for where we can take this relationship. Watch this space...' #whenItCountsCountOnUs



For the second year, Scrap Car Comparison donated more than £11,500 from the company's 'Donate a Car'

scheme. The scheme allows people to get rid of old, damaged and unwanted vehicles and give all or some of the profits to a charity.

Amy Josling, Content Marketing Executive at Scrap Car Comparison said:

'As always it's a pleasure supporting such a fantastic charity.'

We value all the support given to the DSA and would like to thank all of our companies for their help in 2021 including, ASDA, AXA XL, B&Q, Brandwells Construction, Ergonomic Solutions, Givex, Hemingways, Serco, Tesco, Vodafone, Waitrose stores from Exeter to Wimbledon and so many more.

For information on company support and the ways companies can donate to the DSA visit: downs-syndrome.org.uk/CorporateSupport/



Challenge 21

The virtual #Challenge21 challenge is super flexible and super fun. Whoever you are, whatever type of Challenge 21 you can dream up, sign up now and once you've completed your personal challenge, you'll receive a special Challenge 21 medal.

downs-syndrome.org.uk/get-involved/challenge-21/



Ultra Challenges



Are you a regular walker and new to endurance events? Perhaps a seasoned trekker looking for testing adventures? Or even a marathon runner wanting to 'up' your distance? Whether it's along magnificent coastal scenery, or in stunning open countryside, there's an Ultra Challenge for you.

Walk, jog or run at YOUR pace on the Ultra Challenge Series event of your choice. Join 30,000 others of all ages and experience in 2022 for an unforgettable Challenge. It will be rewarding, fun and achievable with your resolve and determination alongside first class support.

Push yourself further - 100km Full Challenge, with Half and Quarter options also available.

downs-syndrome.org.uk/get-involved/walks-and-treks/

Great North Run

After two long years, the iconic Great North Run is back in September. Even the traditional finish line at South Shields is back! Join Team 21 and take on this bucket list challenge in support of the Down's Syndrome Association.



London Marathon Round Up 2021 and 2022 Own Place push

We are so pleased to let everyone know that our 2021 Team 21 London Marathon runners raised an incredible £126k. After two long years of training and waiting, the team were finally able to take to the streets of London, alongside our team of Virtual London Marathon runners.

Thank you all so much for your amazing support.



If you have secured an Official Ballot place in the London Marathon and want to run for us, please contact the fundraising team at events@downs-syndrome.org.uk.



Big Yellow

We have been lucky enough to have been supported by the Big Yellow Foundation since 2018. We asked them to share with our members what supporting the DSA meant to them.

'Big Yellow are happy and proud to support the DSA with the fantastic work they do for their members and members family, friends and carers.'

'Our store teams collect donations from our customers for our Big Yellow Foundation and we match every pound donated. We then pass this on in the form of quarterly grants to our charity partners, including the DSA.'

'The Big Yellow Foundation works with charity partners supporting vulnerable people, such as people living with disabilities, to find employment and create a better future for themselves. In addition to the grants, we are now offering work placements.'

Thank you so much to the Big Yellow Foundation and everyone involved who supports the DSA.



Helpline and Information Centre

0333 1212 300

info@downs-syndrome.org.uk

Our Information Officers are available to respond to calls and emails 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 who have Down's syndrome shape our resources and help to inform our decisions through our inclusive participation activities with DSA Our Voice members. Parents, practitioners and people who have Down's syndrome can also ask us questions on our closed Facebook groups.

We work with affiliated parent support groups in England, Wales and Northern Ireland. Contact us for local support group contact details.

Training

training@downs-syndrome.org.uk

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



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.



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

LANGDON DOWN
CENTRE

www.langdondowncentre.org.uk

0333 1212 300

info@downs-syndrome.org.uk

www.downs-syndrome.org.uk

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Middlesex TW11 9PS

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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



www.ds-int.org