

# journal

147 Autumn/Winter 2023



**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 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: [downs-syndrome.org.uk/our-work/information-services/dsa-journal/](https://downs-syndrome.org.uk/our-work/information-services/dsa-journal/)

# LETTER

from the Chief Executive



Carol Boys

*Welcome to the autumn Journal, I hope you all are keeping well and have managed to enjoy some time away with your families and friends over the summer.*

We continue to be extremely busy here at the DSA and I think this edition certainly reflects that.

You may have heard about, or read, recent stories about new research into ageing in people who have Down's syndrome, as well as new potential treatments and vaccines for Alzheimer's.

We are excited and hopeful about these advances. While it is still early days, these research projects certainly have the potential to improve the lives of those who have Down's syndrome.

We are in touch with the respective research teams and will share all the latest developments here in the Journal, so please do continue your membership to receive all the latest updates.

Self-advocacy remains at the heart of the DSA and with that in mind I would like to say how proud we are of Our Voice Ambassador Emma Bishop who

represented the DSA at the recent UN COSP conference in New York. Emma presented on Easy Read and Voting, and met with the UK Minister for Disabled Persons, Tom Pursglove. She did an incredible job. Similarly, I would like to welcome on board our new Inclusion Advisors, Joe, and Catherine. You can read more about Emma's trip, Joe and Catherine on page 12 and 13.

In May we re-launched our Complex Needs webpage, an invaluable resource for those families dealing with other conditions alongside Down's syndrome, do check it out.

On page 10 our new Specialist Education Advisor, Sharon Smith, talks about inclusive education and the need to keep shining a light on this area.

I would like to say a big thank you to Doctor Liz Herrieven who shares her thoughts, in this issue, on Reasonable Adjustments in Healthcare.

Our members have shared some fantastic stories with us in this edition, from travelling through Europe in a campervan, to modelling in Barcelona, to fundraising, to learning the ancient craft of art blacksmithing.

The My Perspective Awards event takes place next month. Huge congratulations to our finalists. If you haven't seen our shortlist already, please visit our website and look at the wonderful photography our community is creating. Thank you very much to all our supporters who help to make this very important event take place.

To end I would like to congratulate Jen Blackwell from DanceSyndrome on her BEM, what an achievement!

I hope you enjoy this edition of the Journal and please do keep your feedback coming!

Carol Boys,  
Chief Executive

# WELCOME

Letter from Kate Powell

## "Welcome to the Journal."

*Welcome to the autumn edition of the Journal. It is packed with interesting articles, inspiring stories, and the achievements of our wonderful fundraising members.*

It was good to read about the success of Emma Bishop's visit to the UN. What a great Ambassador and role model she is.

Many congratulations to Jen Blackwell on receiving her thoroughly deserved BEM. As dancing is close to my heart, it was amazing to read her story about founding her charity DanceSyndrome.

Well done to the finalists in My Perspective 2023 I look forward to seeing the results in October.

The highlight of my summer was being presented to Pope Francis at the Vatican on World Down Syndrome Day alongside my dance group, Larondina. He climbed down from his Pope-mobile, and with the aid of a walking stick came over to talk to us. It was a magical moment never to be forgotten.

Don't forget to join our weekly lottery, and I wish you all the best of luck!

Kate Powell



Kate Powell

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### ON THE COVER:

Emma Bishop

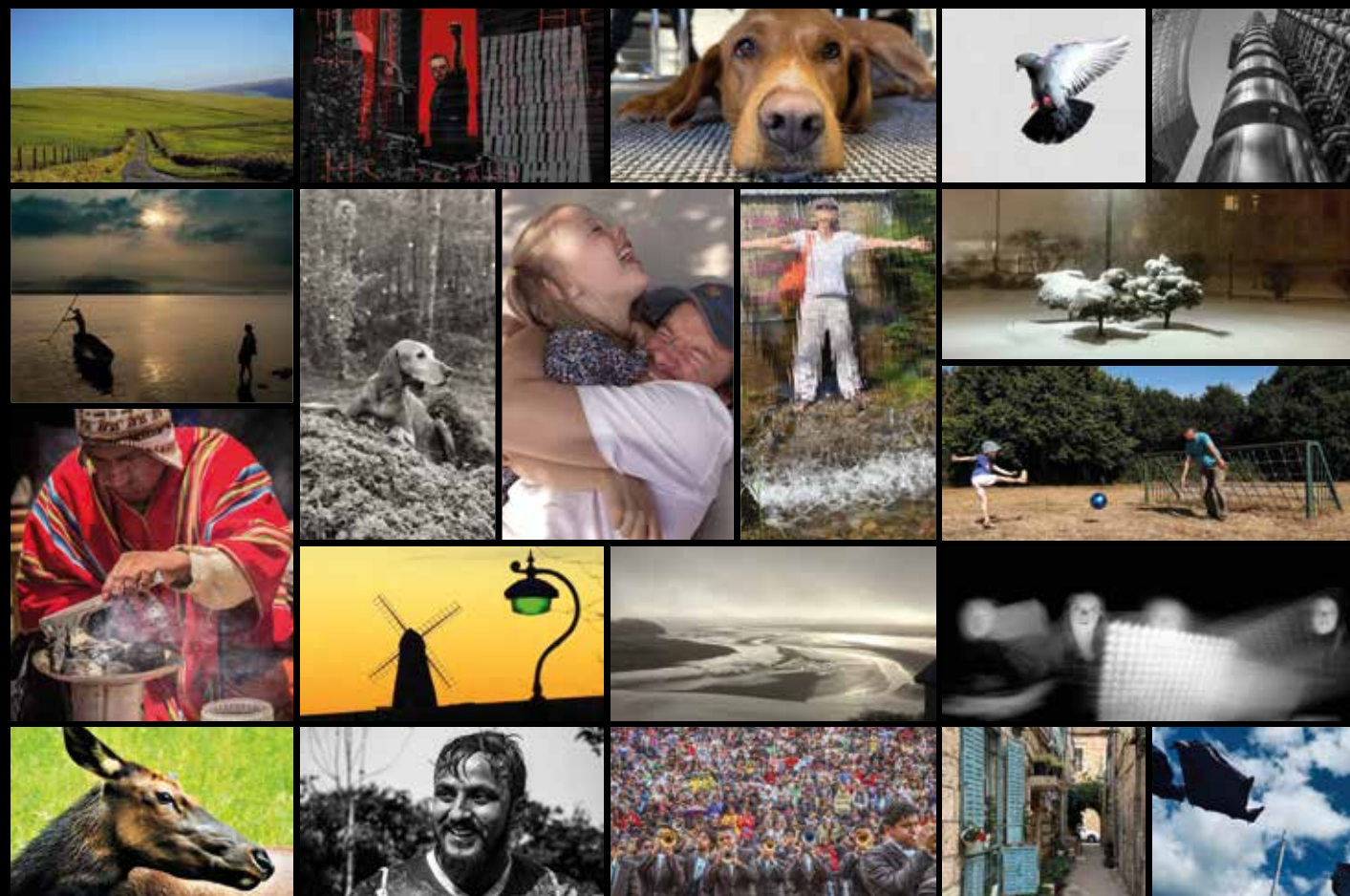
Representing the DSA in New York - see page 12.



# MY PERSPECTIVE 2023



Congratulations to all our competitors who are through to this year's final! Our shortlist is a stunning collection of highly creative photographic work, and we are very excited about announcing our winners at our upcoming awards event on 12 October at LDC.



Adult's Category



Children's Category

We had seven films submitted for our inaugural short film category which were wonderful to watch.

This year, and into next, we are running five public exhibitions of shortlisted photographic work:

Exeter Library:	12 Oct 2023 – 12 Jan 2024
Teddington Library:	17 Oct – 17 Nov 2023
London Hilton Hotel:	22 Jan – 2 Feb 2024
Birmingham Hilton Hotel:	12 – 29 Feb 2024
Leeds Hilton Hotel:	4 – 22 Mar 2024

**Do pop in and have a look!**

## DanceSyndrome founder, Jen Blackwell, receives BEM



*The inspirational founder of a local charity has been recognised with a British Empire Medal (BEM) for services to disabled people in the first King's birthday honours.*

Jen Blackwell is 41 and lives in Chorley. Her greatest passion in life is dance. Jen also has Down's syndrome but has never let her disability stop her from living life to the full. After she left school, Jen and her mum, Sue, spent 10 years searching for the right dance training opportunities that would allow her to follow her dream to be a Dance Leader and performer. After all those years of searching, they couldn't find anything that was accessible for Jen because of her learning disability, so in 2009 they took matters into their own hands and set up their own organisation, Lancashire-based charity DanceSyndrome.

DanceSyndrome's ethos is that disability should never be a barrier to following your dreams. All DanceSyndrome activities are disability led, with people with learning disabilities taking visible leadership roles to inspire people to see what can be achieved when we all become more inclusive.

*Jen said: 'I'm amazed to receive this honour for what I love doing. I'm proud of who I am and the achievements of DanceSyndrome. It's an honour to inspire others to dance and live a life of their choosing. I believe that everybody can dance and do things they love no matter how other people define us.'*

The charity offers weekly inclusive dance workshops, their own accredited leadership training, and high quality and exceptional performances at a variety of events including performing at the prestigious Edinburgh Fringe Festival this August. Find out more at [dancesyndrome.co.uk](https://dancesyndrome.co.uk)



## CELEBRATING JUNE'S 80TH BIRTHDAY!

*In April we were contacted by June's brother Neil. He wanted to tell us about his sister June who had just turned 80!*

June was born in 1943 in Clay Cross, Chesterfield. Our father was in the army, serving in Hull on anti-aircraft guns that protected the docks. June occasionally visited him there, despite the heavy damage that had been inflicted on the city.

June is the eldest of the family and has three brothers (one deceased) and one sister. June remains very active and alert and has never had any serious illnesses.

June's 80th birthday party was a great occasion. Lots of family came, 30 in total, and there were staff and service users from both her residence and the day service she attends.

All together there were about 90 people! June received between 40 and 50 birthday cards and lots of presents as well. There was lots of music from the mobile disco. She was so happy and excited I can't begin to tell you!



# REASONABLE ADJUSTMENTS

## in healthcare

By Dr Elizabeth Herrieven

Consultant in Paediatric Emergency Medicine | Sheffield Children's NHS Foundation Trust  
Honorary Senior Lecturer, MSc in Paediatric Emergency Medicine, QMUL

*You may or may not have heard about 'reasonable adjustments', but they can make a huge difference for people who have Down's syndrome who need to go to hospital or visit the GP.*

The Equality Act, 2010, is a law that was passed to help prevent discrimination against people with physical and/or learning disabilities. It states that businesses and organisations must make reasonable adjustments to allow disabled people to access their services or work within them as an employee. That is to say, they must do what they reasonably can, to help people who would otherwise struggle to get the same experience, care, opportunities, or level of service as other people.

So, what does that mean for healthcare? There are some really good examples of the way reasonable adjustments have been put into action, but there's still a lot of work to be done.

Some reasonable adjustments might be quite generic and of use to everyone, but others depend on knowing what sort of support an individual might need.

For some people, waiting in a busy, noisy waiting area might be too difficult, so a reasonable adjustment might involve finding somewhere quieter to wait (if possible), or giving them the first appointment of the day so the waiting room is likely to be less busy, with less likelihood of a long waiting time. The key word is 'reasonable' – sometimes it's not possible to find a quieter space, particularly in busy A&E departments, but the hospital has a duty to try. Physical access is also important and reasonable adjustments might include ramps, lifts, wider doorways, and railings.

A longer appointment time might also be a useful reasonable adjustment, to allow more time for a person with a learning disability or sensory challenges to be able to get used to the doctor or nurse, feel comfortable in the room, understand what is going on and take part in any examination or tests.

Communication is vitally important for anyone when seeking help with their health. For someone with speech and language difficulties, reasonable adjustments might include the use of 'easy read' leaflets, pictures, photos or symbols, Makaton, or sign language. It might involve just speaking a little more slowly and clearly, avoiding using jargon or complicated phrases, explaining things well and avoiding being in a noisy environment. Another reasonable adjustment that was particularly important during the COVID-19 pandemic was to allow people

with a learning disability to bring someone along to healthcare appointments with them, at a time when most people had to attend alone. For some people, it might be reasonable for a hospital team to allow a family member or carer to stay overnight with a person if they need to be admitted to hospital but would find being on their own particularly difficult, whether due to anxiety, understanding or communication, for example.

Some healthcare teams have put a lot of thought and work into what they can do beyond the basics, to make access to healthcare easier for people with a learning disability. For example, the team at an MRI scanning unit put together a series of photos for a young man who needed an MRI scan but who was very nervous about going to new places. The photos helped form a social story, so the man could learn about the department and what would happen, before he got there. Videos can also be useful, like this one from Sheffield Children's Hospital [youtu.be/c4gVGmllu7c](https://youtu.be/c4gVGmllu7c)



Desensitisation is another way to help make things like blood tests or EEGs (which use electrodes to measure the electrical activity in the brain, a bit like an ECG for the heart) a bit easier to tolerate. This is often led by learning disability nurses and involves breaking down the procedure, explaining things clearly and giving an opportunity to get used to pieces of equipment or sometimes rooms or environments.

Although reasonable adjustments are required by law, they are not always well known about. Lots of work has been done in recent years to raise awareness and remind healthcare professionals about the, often very simple, things they can do to make a difference for their patients. Often, those same adjustments can make things easier for the healthcare professional, too!

The TEACH mnemonic is a widely used example of this and covers a variety of things that can make a difference [hertfordshire.gov.uk/media-library/documents/adult-social-services/teach-reasonable-adjustments.pdf](https://hertfordshire.gov.uk/media-library/documents/adult-social-services/teach-reasonable-adjustments.pdf)

Another version is **STEP IT UP** – aimed for use with neurodivergent patients, so including those who are autistic or have difficulties processing sensations, this focuses particularly on communication (see blog above<sup>1</sup>).

Another framework, particularly for autistic patients, is the Autistic SPACE<sup>2</sup>:

**S: sensory needs**  
**P: predictability**  
**A: acceptance**  
**C: communication**  
**E: empathy**

HELLO, I'M I AM YEARS OLD (DOB xxxxxx)

Important people or things in my life are:

Things I like (e.g. food/drink, sensory, interests, motivators):

Things I don't like/that upset me (e.g. food/drink, sensory, procedures):

INSERT PICTURE HERE

**IMPORTANT**

Things that might comfort or distract me when I feeling scared:

How you will know I am in pain/tummy/tired?

How I Communicate? (See the other sheet in this document for tips):

**HOW YOU CAN HELP ME:**

Getting about:

Toileting:

Eating/drinking:

**PHYSICAL HEALTH**  
(e.g. medication, health conditions, allergies, Equipment).

This hospital passport for children with Down Syndrome has been created by [www.downrightspecial.co.uk](https://www.downrightspecial.co.uk)

**DOWNRIGHT SPECIAL**  
Creating a brighter future for children with Down Syndrome

The LD Pledge was first used in the Accident and Emergency department in Hull to remind not just patients, families, and carers, but also staff about the simple things that can be done to help support patients with a learning disability. It is now in use in many other healthcare settings and has even been made into a YouTube video [youtu.be/xYbcZjdYbG0](https://youtu.be/xYbcZjdYbG0)

There are many different electronic patient record systems in use across the UK and there are national recommendations that alerts should be added to patient's electronic records if they require reasonable adjustments or if they are at increased risk of serious illness. Projects are underway to evaluate how this could work in a more joined-up way nationally, but in the meantime many healthcare organisations have started to put this in to practice locally. In Hull, Downright Special (the local support group) has worked with hospital clinicians to get an alert added to the records of children with Down's syndrome to highlight that they may be at increased risk from sepsis.

How can families and carers help with identifying reasonable adjustments that could be made?<sup>3</sup> Hospital, or health, passports can be useful for this. These are carried by the patient and contain some useful information that can be used by healthcare professionals, such as how best to communicate with someone, how a person might show they are in pain, what might make a person feel less anxious, what might make them feel scared, etc. If you don't have a hospital

passport, ask at your local hospital or your community learning disability team and they can help you get hold of one. Downright Special has put together their own version, which is short and to the point, so easy to read and update when needed.

You could also share some of the resources and examples in this article with your local hospital or GP surgery. It would be great to hear from people who have come across other good examples, too.



### More reading for healthcare professionals...

<sup>1</sup> [dontforgetthebubbles.com/step-it-up-communicating-with-neurodivergent-patients/](https://dontforgetthebubbles.com/step-it-up-communicating-with-neurodivergent-patients/)

<sup>2</sup> [magonlinelibrary.com/doi/full/10.12968/hmed.2023.0006?rfr\\_dat=cr\\_pub++0pubmed&url\\_ver=Z39.88-2003&rfr\\_id=ori%3Arid%3Acrossref.org](https://magonlinelibrary.com/doi/full/10.12968/hmed.2023.0006?rfr_dat=cr_pub++0pubmed&url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org)

<sup>3</sup> [downs-syndrome.org.uk/wp-content/uploads/2020/10/Reasonable-Adjustment-Examples.pdf](https://downs-syndrome.org.uk/wp-content/uploads/2020/10/Reasonable-Adjustment-Examples.pdf)





Chris Rees

# Policy [ 'pole written con

## POLICY UPDATE

By Chris Rees, DSA Policy Manager

*For the second time this year, the DSA were thrilled to find ourselves in the impressive and iconic setting of the UN building in midtown Manhattan. We were there to attend the 16th Session of The Conference of States Parties to The Convention of the Rights of Persons with Disabilities (CRPD) – or ‘COSP’ as it is, fortunately, known for short. COSP is the annual UN gathering of individuals, organisations, and diplomatic missions from around the world to raise and discuss the vast range of concerns, challenges and best practices affecting people with disabilities.*



Taking place over four days in mid-June the format of COSP provided a range of opportunities for attendees. Alongside the formal agenda for UN representatives (mostly held in the General Assembly Hall which you usually see on TV) there was also a full programme of side events. These were spread across numerous conference rooms and chambers in the building, with over 80 separate events held by civil society and Government delegations.

At this year's event we were particularly lucky to be part of a rich and diverse set of organisations representing people who have Down's syndrome from across the world, with several active and engaged self-advocates who were there to share their views, experiences, and expectations. This group included Emma Bishop, from our own Our Voice network who effortlessly managed to overcome jetlag and the potentially intimidating environment to make her own significant mark on COSP. However, it wasn't all work, work, work for Emma – and you can read about how she saw the sights and took over Manhattan on p12.

So, for four long and eventful days our team spoke, shared, networked, presented, and occasionally got slightly lost in the huge labyrinth of the UN building. Our enthusiasm was matched only by our coffee intake, with some of the key highlights of our time at COSP being:

- Emma presenting on the panel of the UN organised 'Easy to Understand Communication Meeting', alongside the President of the UN General Assembly
- DSA's bilateral meeting with Tom Purslove MP, Minister of State for Disabled People
- Emma sharing her experiences on the panel at the 'Promote Democratic Participation, Ensure Inclusive Elections' side event.

We also used the opportunity to bring to COSP the views of our members, to find opportunities to learn and reflect, and to consider how we can further develop our own work in the UK. We attended 16 meetings in all, covering employment, inclusion and participation, ageing, education, health, and democracy. Each meeting

was an opportunity to share examples of our incredible work, hear from other people and organisations doing similar things to ourselves and to develop relationships and network. It was an invaluable experience which will continue to resonate as we move forwards with our planning for the future, and how we support our members in the present.

Meanwhile back in the UK...by the time you read this we expect to be deep in the process of the consultation on the Down Syndrome Act's draft guidance, the next step in turning the aspirations of this piece of legislation into a reality. The work reforming the health service, including the role of Integrated Care Boards (also relevant to the Down Syndrome Act) continues, as does a regular round of government consultations covering issues such as education, safeguarding, transport and the cost of living. We also continue to represent our members views across our involvement in our many voluntary sector networks and through our support to our Affiliated Groups.



## COMPLEX needs

*Our re-launched complex needs webpage is an invaluable resource for information on conditions that may sit alongside Down's syndrome and details dates for our regular parent/carer support sessions.*

You can also read about the stories of other families who kindly share their journey with complex needs on the page.

Do check it out and let us know what you think.



*Jamie is very gentle, caring, and affectionate. He loves to make people smile and he has a beautiful personality.*

Jamie has Down's syndrome and was diagnosed with Autism aged five.

Jamie uses ear defenders or headphones a lot, to help him.

He struggles in groups of people and in new or noisy places and prefers quieter, more predictable spaces.

Songs and cartoons on his iPad or TV are Jamie's favourite things and he can often be found singing along or laughing out loud at something that's tickled him!

Jamie has a severe developmental delay and because of this, and his Sensory Processing Disorder (SPD), he is still in pads. Although Jamie is classed as non-verbal, he does have some language now and when he's relaxed, will use single words or some short phrases. He uses gesture a lot and understands simple sign. Hearing Jamie speak constantly amazes us, as for many years we thought he might never learn how to talk.

Jamie loves swimming, especially under water; maybe it's quieter down there?

He loves bouncing on his trampoline and going to Rebound Therapy, but his favourite place to be is the beach. That's his happy place, all year round, Jamie just loves the seaside!

Whatever Jamie is doing he will always find a way to stim, either by 'pouring' counters or balls, sand, pebbles, even

toys. Stimming is important to Jamie, it helps him to self-regulate and after a long day at school it's the first thing he wants to do when he gets home.

He loves watching the same cartoons again and again and often mimics the funny parts to try and make us laugh!

Jamie is such a lovely young man; he makes us all smile every day and he gives the best hugs. We are all very proud of him!

The Down's Syndrome Association has been a great support to us and I've been lucky to attend many of their courses over the years. Now you can find all this information and much more on their webpage which is such a brilliant resource that continues to grow.

There's also the DSA Complex Needs and Autism page on Facebook; [facebook.com/groups/DSAComplexNeeds](https://facebook.com/groups/DSAComplexNeeds), which is really useful for questions and advice.

Every month I look forward to joining the DSA's online meetings for Parents of Children with Complex Needs and Autism ([downs-syndrome.org.uk/our-work/services-projects/training/parent-carer-meeting/](https://downs-syndrome.org.uk/our-work/services-projects/training/parent-carer-meeting/)). It's lovely to learn new things and chat with people who understand completely the extra challenges life brings when your child has complex needs.

By Jamie's Mum, Ann



Jamie





# AN UPDATE ON THE INCLUSIVE education project

By Sharon Smith, DSA Education Advisor

## Who am I?

Hello! I have recently joined the DSA as an Education Advisor. I am a parent of a young lady who has Down's syndrome who is now at college full-time, having completed all her education in mainstream settings. As well as being a parent, I have co-founded/helped run a Down's syndrome support group, been Chair of our local Parent Carer Forum, and more recently have been undertaking a PhD research inquiry with parents of children who have Down's syndrome, exploring their experiences and understandings of inclusion. I am delighted to be able to put these experiences to use in my new role for the DSA.

## What am I working on?

In 2021/22, the DSA paired up with Down Syndrome International (DSi) to undertake an Inclusive Education campaign. Both organisations have

been collaborating and advocating for more inclusive education for pupils who have Down's syndrome for many years, and the purpose of this project was to both undertake research to understand the current landscape and understandings of inclusion, and to increase awareness of the benefits of the pursuit of inclusive education. During the campaign, a range of blog posts were produced, which can still be found online at: [downs-syndrome.org.uk/news/category/resources-information-training/inclusive-education-for-all/](https://downs-syndrome.org.uk/news/category/resources-information-training/inclusive-education-for-all/)

Following my appointment, we are now looking at the next steps, in terms of how we can take the learning from the previous collaboration with DSi to shape our offering of support and training for people who have Down's syndrome, their parents/carers, and the professionals and practitioners who are working with them in education settings. One of

the first pieces of work is to revisit the findings of a research survey that was undertaken, to ascertain what areas we could offer more support or education in.

## What did people tell us?

The survey attracted 335 responses, of which two thirds were from parents/carers. The next biggest cohort was teachers/learning support assistants. Twelve learning disabled people completed the survey and only a very small number of Headteachers, Senior Leaders or School governors responded, and we therefore plan to undertake further research with these groups.

We asked respondents to tell us about what they thought inclusion meant, examples of where it had gone well or not so well, and what training or support they thought schools and teachers might need.



## Teachers/learning support assistants

For inclusion to occur, it requires a whole school commitment and culture shift, with a need for the school leadership to be driving the inclusion agenda. Unfortunately, some teachers and learning support assistants do not feel that they have had enough training to include all disabled children in their classroom. They are also aware that it can be challenging providing individual tailored approaches within large classrooms with limited resources. They highlighted too how there needs to be help for all children in the classroom to know how to accept each other, whatever their differences might be.

Despite raising these challenges, those who responded to the survey also talked about optimistic aspirations for inclusion, and described positive experiences, for example:

*'Based on my experiences of having children with intellectual disabilities in my mainstream class over the last 25 years has only ever been a positive experience for EVERYONE. It's a two-way street and everyone benefits. My hope has always been that the time any child spends in an inclusive school, equips them for later life; that it teaches them what a really equal society looks like.'*

## Parents/carers

Whereas teachers and learning assistants focussed on their skills and resources, the responses from parents/carers focussed more on interpersonal relationships, for instance between the parents and the school or between their child and their peers. They discussed a desire for opportunities for their children to engage with whole class learning, alongside peers rather than sat with a learning support assistant or in a separate space, and for their child to be



able to access extracurricular activities, school trips, end of term celebrations and sporting activities too. None of these aspects are necessarily things that require formal training or additional funding to achieve, rather it again comes down to a desire to be inclusive and to consider the engagement of all children who are within the classroom.

Despite highlighting the challenges of inclusion in mainstream education, parents also reported positive experiences, demonstrating that inclusion can happen when everyone works and learns together, for example:

*'We felt that we were learning together and overall were very happy with the support given and drive for inclusion. Our son not only progressed and enjoyed his time there but made meaningful friendships and was definitely a valued member of the school community. However, so much depended on the SENCo.'*

We would love to hear from you if you have experiences to share relating to these areas, that we might be able to use as we develop the new training materials, or if you might like to be involved in the project as it progresses. My email address is: [sharon.smith@downs-syndrome.org.uk](mailto:sharon.smith@downs-syndrome.org.uk)

Please do get in touch!

## What next?

Over the coming months we are going to be refreshing our training materials and running some online events, which we would love for you to get involved with. We will be basing these on the areas of focus that came out of the survey, for instance:

- The benefits of inclusion.
- Developing friendships and social skills.
- Assessment/monitoring progress.
- Adapting homework.
- Inclusion in all activities of the school – e.g., extracurricular activities, school trips etc.
- Adapting the curriculum to make it disability inclusive – e.g., whole class teaching about disability histories within a history syllabus, rather than differentiation of materials for one child.
- Effective communications & relationship building between home and school/college.





# CONVENTION ON THE RIGHTS of persons with disabilities

by Emma Bishop

*Self-advocate and Our Voice Ambassador, Emma Bishop, was in New York recently to attend the annual UN Conference of States Parties to the Convention on the Rights of Persons with Disabilities (COSP). Here she tells us about why she was there and shares her experience.*



**What were you speaking about at COSP 16?**

I gave two speeches: Easy Read and Voting.

Easy Read is information which has bigger writing and bigger pictures. It means that people who have a learning disability can actually read and understand it. It's important.

People who have a learning disability have the right to vote, and the right to understand what they're voting for. Supporters need to explain the election and who the candidates are.

**How did you feel about speaking in front of so many people?**

I felt overwhelmed and shocked, but really excited and powerful inside me too. I got more confident over time. It felt like everyone was listening to me. People came up to me afterwards and said I had done a fantastic job to speak in front of so many people. They were surprised at what I did.

**Do you think it is important to attend these kinds of events?**

I would like to do some more events like COSP. I want to travel around different countries.

I let people know what my life is like in the UK. I want to give people who have a learning disability the chance to go out more to get information about all sorts of things. For example, being able to get Easy Read information to explain what everything is.

**How did you feel meeting UK Minister for Disabled People Tom Pursglove?**

I was so glad to meet Tom Pursglove and speak to him in person.

I'm proud that I told him about the work I did in New York as well as my role in Our Voice. He's a nice man and spoke really clearly. I could understand it all.

**What changes would you like to see for people who have learning disabilities?**

I would like to help people who have learning disabilities to give them the right information on things. I would like to run a workshop to stand up for myself and tell people about what I've done.

**What was the best bit about your trip to New York?**

I had a high-five with the Nelson Mandela statue in the lobby of the UN building! I liked that.

I did some sight-seeing and saw New York. I met a Minnie Mouse character in Times Square! I spent time with Abby from the DSA.

I miss it all. I was so proud of what I did, and I made some good friends to talk to.

I have been interviewed several times since I got back to England and was even on the radio!



# OUR NEW INCLUSION ADVISORS

*In July 2023, two new employees started work at the Down's Syndrome Association. Joe and Catherine both have Down's syndrome and are our new Inclusion Advisors.*

People who have learning disabilities are excluded from policy-making processes due to inaccessible meetings, consultations, and information.

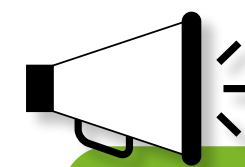
The DSA and Down Syndrome International are working together on a new and innovative project based on Listen, Include, Respect (LIR) - internationally recognised

guidelines for including people who have learning disabilities. Many organisations have already begun to implement LIR guidance in their work, including the United Nations.

Our Inclusion Advisors are being trained on the LIR guidelines and will develop a UK-specific training package. They will use this to

support government departments and linked external agencies to transform processes to make sure they are accessible and inclusive.

Their practical guidance will cover Easy Read information, good support, and how to make meetings inclusive.



Let's meet Joe and Catherine:



Joe

*Hi, I'm Joe and I live in Yorkshire. I have a fierce love of performing and the creative arts – the whole spectrum including movies, musicals and music itself. I love physical theatre dance!*

*At college I became a student representative to campaign for inclusive education and help everyone have a better time. Since then I've taken on other leadership roles because I'm really passionate about making a positive difference for all who need it. These gave me experience of work meetings.*

*When I was younger I came to learn quite a bit about what it means to represent your own community in different ways, from women's empowerment to nature and wildlife, and people of different personalities and walks of life. My favourite wildlife lives in the ocean, especially killer whales, or orcas. They have been misrepresented because of their name, they can actually be really friendly. I have been inspired by movies such as Free Willy and The Little Mermaid, which have caused me to want to focus on conservation. I have adopted a whale who lives in OrcaLab in the Johnstone Strait in Vancouver, Canada.*

*I joined Our Voice with the DSA in 2020. I love having an open mind and I'm excited to use this to make a positive difference in my new role as an Inclusion Advisor.*



Catherine

*Hi, I'm Catherine and I live in Norfolk. Before I found Our Voice, I often watched the news, Question Time, and Prime Minister's Questions about what is going on in politics. I have strong opinions on making the world a better place to be for people who have Down's syndrome. During lockdown I was looking for something that I wanted to do and all I found was Our Voice, so I started working with them in 2020. This is something that I want to do because this is my voice to change the world.*

*I like being social and being with my friends. My passion is dancing; I like contemporary, ballet, musical theatre, and tap dance. I do a lot of different dance styles. I have some performances coming up, for example at my local theatre. Because I'm a dancer, I love watching Strictly Come Dancing.*

*Before I came to the DSA I volunteered in various places. An Oxfam shop, a café in a conference centre, and Notcutt's Garden Centre. Most recently, I have been helping at Able2B, an inclusive gym. I clean the equipment and mirrors and help support the clients, who all have disabilities. It's amazing because it's inclusive to all different abilities, like cerebral palsy, autistic people, and learning disabilities. There are people of all ages, from children to older people. They work with schools as well.*

*When it comes to my new role, I didn't see this opportunity coming and I felt amazed. After I got used to the idea I felt good about it, because I can make a change and stand up for all people who have Down's syndrome.*



*The DSAActive DSEngage Programmes continue to be busy with new partner organisations, sessions and activities.*

Taking part in any activity, whether it's leisure, recreational or sporting, can benefit physical and mental health and the well-being of everyone involved. New activity opportunities as well as established sessions continue to be supported by the DSAActive Programme. The importance of children and adults having the opportunity to take part within a session that best suits the needs of the individual is a value shared by our DSAActive Partners. The changes made after the DSAActive Programme review enables DSAActive to support organisations to successfully participate in a range of session types, to include Down's syndrome specific sessions, learning disability sessions, open mixed ability sessions etc. If you know of a session taking place that the DSAActive Programme could support, please get in touch with DSAActive [dsactive@downs-syndrome.org.uk](mailto:dsactive@downs-syndrome.org.uk)

### Date for your diary:

The first British Down Syndrome Swimming Championships was held in November 2022 and was a huge success. The event will return to the K2, Crawley on 18 and 19 November 2023. More information can be found at [Sign Up 2 | Down Syndrome Swimming Great Britain \(dss-gb.org\)](#) or you can email specific questions to [britishdsswimmingchamps@gmail.com](mailto:britishdsswimmingchamps@gmail.com). This event is great not only for participants but also spectators, so please do come along and support the event.

We continue to have a great time at the DSA DSEngage online sessions. All sessions are free and information about the session and how to book can be found on the DSEngage webpage [DSEngage - Down's Syndrome Association \(downs-syndrome.org.uk\)](#)



Craig

## DSEngage Nature Group

DSEngage Nature Group is a new DSEngage activity that started in the summer. DSEngage Nature Group will share ideas and activities that help us enjoy being outdoors and being in and around nature. Enjoying nature is good for the health of our body and for our mental health and well being and the first activity was growing bright and cheery nasturtium flowers from seed.

We hope that everyone who took part in the activity enjoyed growing nasturtiums as much as we did. Huge thanks to Craig who emailed us to tell us how much he enjoyed the Nature Group activity. He sent us great photos of his nasturtium and of his trip to his local gardens.

Craig was kind enough to answer some questions about the Nature Group activity:

Hi Craig, thank you for your email and photos. Your nasturtium look fantastic! The flowers are beautiful and your plant looks very healthy.

Did you enjoy the growing nasturtium seeds activity?

Yes I did very much.

Did you grow the seeds in a pot first or did you put them straight in the ground?

In pots on windowsill first. I feed the flowers with Miracle Gro one time a week.

What activities do you like to do in your garden?

I like digging planting watering and feeding plants also I like bat and ball games.

Do you enjoy being in your garden?

I do yes when it's not raining! I like being outside and I visited the Coronation Garden built for King Charles where I live.

How does it make you feel to be in your garden?

It's fantastic seeing the plants and flowers grow.



# DSACTIVE NEWS

*We really enjoy reading emails and looking at photos sharing the latest news from DSAActive supported sessions and teams. Here are a few updates from the past six months:*



## Brentford Penguins

Congratulations to Vickie and Allan who were surprised live on TV on the BBC's The One Show. Every

week The One Show like to say One Big Thank You to someone who has gone the extra mile to help others in their community. The Brentford Penguins founders were thanked live on TV for setting up the Brentford Penguins as well as two walking football teams.

**Congratulations to Vickie and Allan from everyone at the DSA and well done to the Brentford Penguins players who were also live on TV and managed to keep it all a secret!**



## Bristol DS Football

The team chose to finish the season in style by organising an end of season trophy presentation. Sam their coach explained that it was a great opportunity to celebrate all the hard work and brilliant teamwork shown by all the players throughout the last year.

**Well done on a great season to the Bristol DS Football players, coaches Sam and Mark and everyone involved in making these sessions such a success.**



## North London United

North London United enjoyed a team trip to Fulham FC Training Grounds in June to take part in the Fulham Badgers friendly football festival. Players enjoyed a pre-game warm up and football drill session before taking part in matches. North London United Coach, Harold Bennett, told us that the players enjoyed the matches and meeting other players and families. The festival was a great social occasion as well as footballing opportunity.

*'It was a good day all round and we are looking forward to hosting the next friendly matches.'*

**Great team photo North London United. It is great to hear that you had a good day!**

## Newcastle United Foundation Down Syndrome Team

*The team were excited to be invited back to Spain to take part in their second Donosti Cup Tournament at the Anoeta Stadium, home of Real Sociedad.*

The Donosti Cup is Spain's top soccer tournament and attracts over 350 teams from 23 nations every year. This year Newcastle was the only team representing Great Britain! The team got off to a great start at the exciting opening ceremony with a lap around the pitch whilst being clapped and cheered by almost 10,000 people. The team loved it, especially all the cheering from the crowd.

On the first day of fixtures Newcastle played a team from France and then the hosts Real Sociedad! Two brilliant games which included Newcastle scoring a goal worthy of goal of the tournament from the halfway line! The team went into their last game

knowing that if they won (they were playing a team from Mexico) then they would be crowned champions! It was a tight nervous game ending 0 - 0 and so they had to have a penalty shoot-out! The team handled the pressure really well. They were fantastic. They won the shoot out and took the Donosti Cup back to Newcastle proud and very worthy winners.

Coaches Mark Daglish and Steven O'Neill hope that the team will be able to parade the trophy to a sell out crowd at St James Park when the Newcastle United 1st Team hold the Sela Cup. A brilliant opportunity to show off their fantastic achievement.

**Congratulations from the DSA to the Newcastle United Foundation Down Syndrome Football Team and to everyone involved in this trip. We have seen the photos and the official video and it looks like an amazing tournament and that you all had a great time!**



Search YouTube for 'Aftermovie Donosticup 2023' to watch the official video of the event. You'll see the guys from Newcastle at 4:45 but do watch the whole thing to get a feel for what a fantastic tournament this is to be a part of.



# WORKFIT update



WorkFit Manager Alison and WorkFit Officer Becki had lots of fun attending The Big Logistics Diversity Challenge at the start of the summer! It was great to connect with so many organisations from the logistics industry, all demonstrating their passion, support, and enthusiasm to improve equality, diversity, and inclusion, as well as celebrating the business benefits attained by establishing a diverse workforce. It was also wonderful to see Freya from the GXO Logistics, Inc. team!



Adriana Pepe

## Welcome to Adriana Pepe!

Welcome to Adriana Pepe who joined the WorkFit team earlier this year as WorkFit Officer for West London and the Western Home Counties.

Adriana is passionate about inclusion and is excited to be part of the team. We are also delighted to welcome back Molly Keal to her role as WorkFit Officer for the North West.

Check out our latest updates on the 'News' section of the WorkFit website, which covers the highlights for our candidates and employers each month. You'll also find a recent blog about Lucy, who completed a supported internship with East Riding

of Yorkshire Council. This is a great example of all parties working in partnership to support Lucy and give her a valuable experience.

Lucy told us: 'I have got so much ability and want to work hard to make people proud of me. I know that working hard will help me to get even better at my job. I feel so proud of myself for the great progress I have made, I want to learn even more new things so I can be given more tasks.'

Her hard work has clearly paid off, as she has progressed to a permanent paid position!



A big thank you to all our partner employers for their ongoing support of the WorkFit programme.



We are pleased to announce that two of our WorkFit candidates were finalists for 'The People's Award' in the National Learning Disability & Autism Awards 2023! Congratulations to Youssef, who works at Greggs in Cardigan, West Wales, and James who works at Hilton London Heathrow Airport. Congratulations also to our partner employers GXO Logistics, Inc., ODEON Cinemas Group and The Gym Group who were also finalists for the 'Employer of People with a Disability Award'.

Finally, the WorkFit team itself made it to the final of the 'Making a Difference Award (Team)'.

The National Learning Disabilities & Autism Awards celebrate excellence in the support for people with learning disabilities and aim to pay tribute to those individuals or organisations who

excel in providing quality care. It is an honour to be recognised.

It was a pleasure to be invited to participate in Principle Cleaning Service's 'Equality, Diversity and Inclusion in the Workplace' seminar. WorkFit Officer Lydia gave a presentation about our WorkFit programme and discussed the successful placement of three team members into onsite roles, with plans to develop more opportunities at their client sites. Thank you to Principle Cleaning Services for their continued support.

Congratulations to all the WorkFit candidates who have started new roles this year. We have supported candidates into a range of varied and interesting jobs over the past few months such as Daniel who is a host at the Bridge Theatre in London, Charlotte who is a team member at Greggs in Cardiff, Max who has a Front of House role as a 'Nandoca' at Nando's Yeovil, Charlotte who is a Receptionist at Tesco HQ in Hertfordshire and Aimee who started

an exciting opportunity with Thornton Academy of Dance in Middlesbrough as a Teaching Assistant and Vlogger.

Aimee told us: 'Thank you so much, this is my dream. My family are so proud, and I will work hard.'

Good luck everyone!

To find out more about WorkFit and how we support people who have Down's syndrome to access meaningful work opportunities that can benefit the rest of their lives, please contact the team on **0333 12 12 300** or email us on: [dsworkfit@downs-syndrome.org.uk](mailto:dsworkfit@downs-syndrome.org.uk)

For more information visit the WorkFit website:

[dsworkfit.org.uk](https://dsworkfit.org.uk)





*A huge thank you, and much kudos, to our intrepid 2023 skydivers who between them raised a staggering £68,879!*

# WORLD DOWN SYNDROME DAY SKYDIVE

*A special shout out goes to our new Ambassadors, Aitch and Joanna Chimonides, who courageously donned the blue sky suit and did some free falling for the DSA this year, raising not just lots of money, but also vital awareness for Down's syndrome.*

BRIT Award winner and multi-platinum-selling rap artist Aitch became an Ambassador for the DSA in October 2022 after supporting the charity with a generous donation from the budget of his music video for his track 'My G' featuring Ed Sheeran. This song is dedicated to his younger sister Gracie, affectionately known as 'G', who has Down's syndrome, and was filmed in the DSA's beautiful Normansfield Theatre at the Langdon Down Centre.

Instagram star, model and influencer Joanna Chimonides joined the DSA as an Ambassador in May last year. Her connection to the charity comes from her happy childhood memories of her uncle who had Down's syndrome.

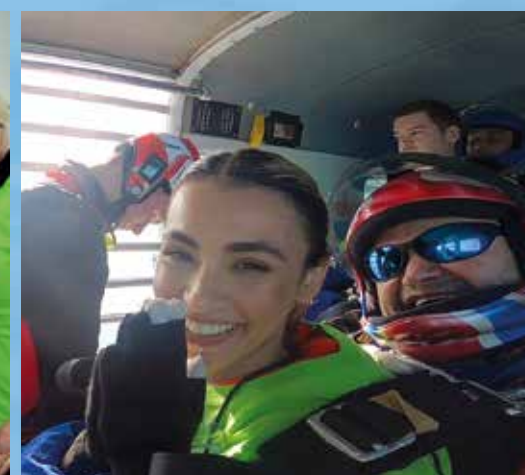
## Feeling inspired?

Then why not take that leap of faith and join us in Salisbury for our annual WDSD celebration in the sky on 23 March 2024.



*To find out more  
visit the skydive  
tab on our website*

[downs-syndrome.org.uk/  
skydives/](https://downs-syndrome.org.uk/skydives/)





# LONDON MARATHON

A massive thank you and congratulations to our fabulous London Marathon 2023 runners: Laura, Stephen, Michelle, Ben, Tom, Georgia, Claire, Paddy, Harry, Danielle, Phil, Dan, Anne, Ian, Caroline W, Emily, James, Caroline S and Luke. Our amazing Team21 runners raised an incredible £70,000!



If you have been successful in the TCS London Marathon ballot and would like to join Team21 and run in one of our vests, please email [events@downs-syndrome.org.uk](mailto:events@downs-syndrome.org.uk)



Play our £1 lottery to be in with a chance of winning up to £25,000!



## WEEKLY LOTTERY

Do you fancy:  
A once in a lifetime holiday?  
A car upgrade?  
That kitchen extension?



[downs-syndrome.org.uk/get-involved/lottery/](https://downs-syndrome.org.uk/get-involved/lottery/)

Then why not join our weekly lottery so that:

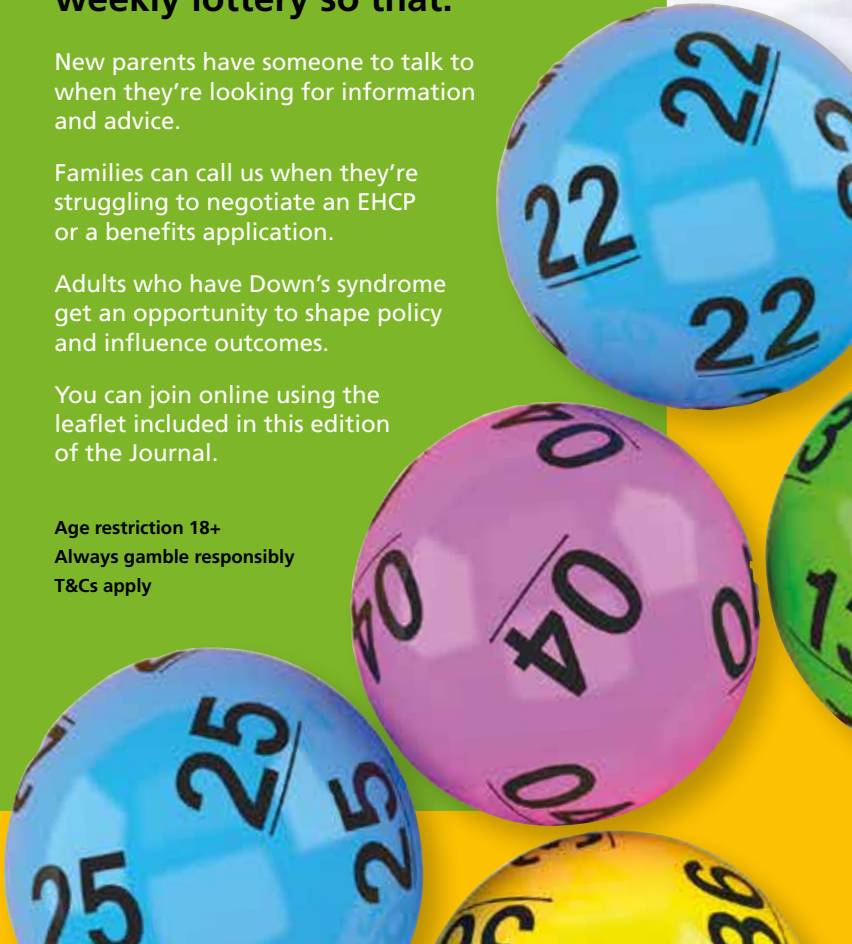
New parents have someone to talk to when they're looking for information and advice.

Families can call us when they're struggling to negotiate an EHCP or a benefits application.

Adults who have Down's syndrome get an opportunity to shape policy and influence outcomes.

You can join online using the leaflet included in this edition of the Journal.

Age restriction 18+  
Always gamble responsibly  
T&Cs apply





# SUPPORT FOR WORKFIT

## from Hilton Foundation



*Hilton has been partnering with the DSA's award-winning employment programme WorkFit for over five years and have been hugely supportive of our aims to support people who have Down's syndrome into meaningful and fulfilling employment opportunities.*

This year, the Hilton UK Foundation has kindly given us a grant to enable us to continue and expand our valuable work with the innovative programme. This means that the people that we support can secure work in jobs they want and enjoy, undertaking work that interests them, and for which they have a particular aptitude.

Through securing work, people who have Down's syndrome increase their circle of friends and contacts and often

develop additional friendships outside of work as well as accessing new social activities through work. Self-esteem and confidence increase, supporting both personal and professional development and contributing towards good mental health. Earning money increases independence and can lead to living more independently. Additional benefits include more community involvement through work, particularly in roles that include interaction with the public and members of the local community.

Indeed, for many people who have Down's syndrome, work-related support from other agencies has been very minimal, and for some, WorkFit has been the only source of employment advice and support they have received.

**Alison Thwaite, WorkFit Employment Development Manager commented:**

*'We are hugely grateful to the Hilton UK Foundation for recognising and supporting the success of WorkFit as we expand our reach and support even more people who have Down's syndrome to fulfil their career ambitions.'*

**Steve Cassidy, Board Chair of the Hilton UK Foundation said,**

*'Our founder Conrad Hilton believed that hospitality could be a force for good in the world, and to this day, we continue to honour this legacy, partnering with organisations committed to creating a better world to travel and building a brighter future for the next generation.'*

*This mission sits at the heart of the Hilton UK Foundation, and we're delighted to award a grant to the Down's Syndrome Association's WorkFit programme, building on our existing partnership to help people with Down's syndrome find meaningful employment in the hospitality industry.'*

*We're really proud to support this organisation's incredibly valuable work, which truly makes a difference to young people's lives.'*



**The DSA greatly values the support of corporates for the work of the charity. For information on ways companies can get involved and support the charity visit [downs-syndrome.org.uk/get-involved/](https://downs-syndrome.org.uk/get-involved/)**

## NINO MODELLING AND SWIMMING

*Hello everyone, I am Nino Genua, I am 24 years old, and I recently received a diagnosis of Mosaic Down's Syndrome.*

My mum didn't find out I had Down's syndrome until I was nearly six months old, it was when I went into hospital at five months old with severe reflux that a blood test was taken because the doctor thought I might have it. Mum wasn't told about the test at the time, no one had mentioned it at all.

Then when she took me to a discharge clinic the doctor told her I had Down's syndrome.

She took me to an appointment with a geneticist who said it was likely I had Mosaic Down's syndrome but needed further tests to confirm. Mum said she refused the testing because I had been through enough testing during my hospital stay, she just wanted to take me home.

I am a competitive swimmer with the Bristol Sharks, to allow me to swim in the Mosaic Down's syndrome category races in certain competitions I need medical confirmation of the diagnosis.

The request for testing started nearly three years ago but due to Covid and lockdown the testing was halted.

Just after Christmas 2022 my Geneticist called to say testing had resumed and she would be sending the test to us for Mum to do and return to our local hospital labs.

Then in April we had a Zoom call with her where she gave us the results that yes, in the cells, that had been tested it showed a mixture of two and three chromosomes resulting in a confirmed diagnosis of Mosaic Down's syndrome.

I will be competing in the next British Down's Syndrome Championships this November in Crawley in the Mosaic Down's syndrome category races for the first time. I'll let you know how I get on.

The photo is of me at the British Down's Syndrome Championships in 2022.

I am a model with Zebedee Talent and got sent to Barcelona for a job for Zalando.

I had the best time and love being with the other models and being part of the photoshoot.

Mum came as my chaperone and the client put us in a gorgeous hotel in the centre of Barcelona.

Everyone on the production team were so supportive and made me feel really welcome on set.

I was so proud of myself for being a model and being able to do a job that they asked me to do.

It was great to go to Barcelona and I had lots of fun.

Mum and my sister Lia say they are so proud of me.

Hope you like my photos.







## MY APPRENTICESHIP

*Jessica is an art-blacksmith and lives in Ireland. Here she tells us how she is learning her craft from her father and establishing herself as an artist in her own right.*



**Could you please tell us what made you want to become an art-blacksmith? It is such an unusual and interesting profession!**

I always saw my father in the forge. I thought he looked really cool and strong. And I wanted to be like him, I wanted to bend metal too. He asked me to help him and it was great fun and after school I thought it would be really cool to always work with him.

**Could you tell us about your apprenticeship, for example how long it is, what is involved?**

I don't know how long my apprenticeship will take. I just go into the forge, and I listen to my dad how I have to stand, how I have to move my body and the hammer and how hot the iron should be. I already learned to start the fire and how to put on my leather gear. To be safe is very important in the forge. My dad teaches me loads of things and I think he is a really good teacher

**What is the best part of learning to become an art-blacksmith?**

The best part is spending time with my dad. And that I can do what I want. I can make shapes how I want them whenever I want them.

**What is the hardest part of learning to become an art-blacksmith?**

It is so hot and it is hard work. I am always getting sweaty and sometimes my muscles hurt. But my dad says it is great to achieve things with hard work. And I love to forge the pendants and I love to forge the figures. So I think my dad is right.

**Blacksmithing is a long tradition in your family, what does this mean to you?**

I don't know, my dad just asked me to help him in the forge when I was still young. And now I make figures and pendants and I think that's really cool. And in Berlin at the Special Olympics I had a big tent with all my figures and people called me a hero and a superstar! They think it is amazing that I am a blacksmith. They said they love my figures and my message and that my message was touching them and that makes me very happy.

**We looked at your sculptures on your website and they are amazing, can you tell us a bit more about the meaning behind them for you?**

My message is: 'We're all different; We're all perfect.' I want my sculptures to make people feel happy, because I like everybody and I want them to know.

**What inspires you in your work?**

I want to make people happy and tell them they should be happy. I hit the iron with my hammer as I feel it. But I feel different and I hit different every day. We are all different and when I cool my figure in the water and it's cold and I look at my figure that I forged I think it is wonderful all the time.

**What does Born Transcendent mean to you?**

I think it is so cool! We're all different, we're all perfect and people with Down's syndrome are all perfect. I met so many other people with Down's syndrome in Berlin and it was so cool! My friend Marina from Malaysia came all the way to visit me. She said my work was amazing and that she loved my message. It made me so happy and I feel very proud to speak for all people with Down's syndrome.

**Your message to the world is 'We are all different; we are all perfect', can you tell us a bit more about what this means to you?**

Well, I think we are all different but I like everybody and want them to be happy. And I am proud to be like I am and everybody should be proud to be as they are.

**What do you hope to achieve in the future?**

Oh, well, my mother is from New Zealand, my dad is German but we all live in Ireland and I want to go everywhere and give people my sculptures and make them happy. It would be so cool!







# THANK YOU BETHAN

*Hello, my name is Bethan, I am 28 years old, and I have T21.*

I would like to make this donation to the Down's Syndrome Association.

Sadly, my lovely uncle Steve died suddenly in January 2023.

My Uncle Steve's funeral day was very sad, but we made a great celebration of his wonderful life.

I made a speech for my uncle at his funeral, and I was a bearer too, I was very proud to speak about how much I loved him.

We let our family and friends know that they could make a donation to the Down's Syndrome Association if they wanted to.

My Uncle Steve helped me a lot in my life, he was always very proud of me, and of all the great things I have achieved.

He would be very happy that I can send this money to help the Down's Syndrome Association to support other people with T21.

I have sent you my favourite photo of me with Uncle Steve and Aunty Sue.

Thank you very much for all that you do.

Bethan x



## Billy's pouch

*Billy decided to do some fundraising for us, here's how he did it.*

**1. Congratulations on your fundraising efforts for the Down's Syndrome Association and thank you! Why did you decide to raise money for the DSA?**

I wanted to help other young people to be like me.

**2. How much money did you raise?**

We raised £1000.

**3. Why do you think it is important to raise awareness of Down's syndrome?**

Some people who haven't got Down's syndrome don't understand the ups and downs of having Down's syndrome.

**4. Tell us a bit more about your work? How long have you worked at The Shop?**

I've worked at The Shop since August 2022 – I work hard selling the sweets, cleaning and tidying, check the bathroom and take the money.

**5. What do you enjoy most about working there?**

I most enjoy sorting the sweets, particularly the bright colours.

**6. Why do you think it's important for people who have Down's syndrome to be able to work?**

Have to do something. Have to get out and have to keep busy. Other people need to see and understand Down's syndrome.

**7. What other hobbies/activities/sports do you enjoy?**

Football outdoors. Gym, weightlifting, boxing and cardio. Games, playing music.

**8. Is there anything else you'd like to say to our readers?**

- Believe in yourself
- Be who you are
- Be mature and serious in a good way
- Talk loud and clear
- Try your best and work hard

## ON THE ROAD with the Cook family

*We recently received an email from the Cook family, who have packed up their life in Worcester and are spending a year travelling around Europe and beyond, in a motorhome.*

**We asked Lizzy about the trip.**

**What do you like about travelling around the world in Gilbert?**

The best thing about travelling is going to lots of new and exciting places and being able to park wherever we like (within reason). I love going to new playgrounds in different counties we've been to, the best one was in Spain with a giant tube slide.

**What's the best place you have been to so far?**

Morocco was brilliant, we went to the Sahara Desert and went camel trekking across the sand dunes. I also love the beach and playing in the sea as long as it's not too cold!

**What are your hobbies and interests?**

I love drawing and painting; my favourite colour is black! I have also learnt to ride my bike without stabilisers while we've been travelling, I just need help starting but I'm practicing with my Dad. I really like stories and enjoy listening and reading books especially when we're travelling.

Julia tells us the motto of their trip has become 'I CAN'.

We've all faced different challenges and the kids are starting to realise that they can do nearly anything, if they just tell themselves that they can, and give it a go. That's how we got here in the first place!

We've been road-schooling the kids and are also supporting Lizzy with her speech and language. However, they're getting a much wider education through the amazing people we've met, the experiences we've had and the beautiful places we've been.



Julia Cook and her husband Tim wanted to give their children William, aged eight, and Elizabeth (Lizzy), aged six, the opportunity to see the world from a young age.

They've been travelling in their motorhome, affectionately named 'Gilbert' for nine months now. They've been to three continents, visited 14 countries and driven more than 18k kilometres... and counting.

**If you'd like to find out more about the Cook's adventure, you can follow them on Instagram @family\_road\_trip\_Europe or you can read their blog.**





## Helpline and Information Centre

0333 1212 300

[info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

0333 1212 300

[info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

[downs-syndrome.org.uk](http://downs-syndrome.org.uk)

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

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

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](mailto:training@downs-syndrome.org.uk)

We offer a wide range of co-produced training events and support meetings for individuals at every stage of their lives, in a variety of formats, for people who have Down's syndrome, parent carers and professionals.

[downs-syndrome.org.uk/Training/](http://downs-syndrome.org.uk/Training/)



## Get active

[dsactive.org.uk](http://dsactive.org.uk)

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



## Employment

[dsworkfit.org.uk](http://dsworkfit.org.uk)

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



[langdondownmuseum.org.uk](http://langdondownmuseum.org.uk)  
[facebook.com/LangdonDownMuseum](https://facebook.com/LangdonDownMuseum)

**LANGDON DOWN  
CENTRE**

[langdondowncentre.org.uk](http://langdondowncentre.org.uk)



[ds-int.org](http://ds-int.org)

## Founder

Rex Brinkworth MBE, BA,  
Cert Ed, DCP

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## The more members we have, the stronger our voice

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