

journal

150 Spring/Summer 2025



Editorial Board

Carol Boys OBE
Kate Potter
Gillian Bird
Rachael Foster

Down's Syndrome Association Journal

Down's Syndrome Association
Langdon Down Centre
2a Langdon Park
Teddington
Middlesex TW11 9PS
Editorial 0333 1212 300

info@downs-syndrome.org.uk
downs-syndrome.org.uk

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.

Copyright

© 2025 by the Down's Syndrome Association. All rights reserved and all commercial use of the contents prohibited except as expressly authorised, in writing, by the Association.

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/

COVER IMAGE:
Daniel Barnes

LETTER

from the Chief Executive



Welcome to the March 2025 Journal.

I hope you are all keeping well and are looking forward to spring. I certainly am!

We continue to be extremely busy here at the DSA.

First and foremost, I must extend my sincere gratitude to our courageous Kilimanjaro fundraisers. The climb was not without significant risks, and I cannot thank them enough for taking on this challenge and raising money and awareness for people who have Down's syndrome.

In December I was honoured to receive my OBE from His Majesty King Charles III at a ceremony at Buckingham Palace and I would, again, like to thank everyone who worked so hard on my nomination. This award does not simply recognise me, it will also support and lend greater weight to our ongoing work.

At the end of January we launched our updated Dementia Workbook, authored by Dr Karen Dodd. The launch event was attended by 180 people. This resource is a vital guide for many of our caregivers and I would like to thank Karen for her time in putting this together and leading the launch.

In this issue we also spotlight several other important new health resources, including a brilliantly detailed piece on epilepsy by Dr Liz Herrieven.

We explore housing options for people who have Down's syndrome on page 14 and share a fantastic story from one of our members, Sam, on how he got his own place through the HOLD scheme. We also share helpful information on how to make a complaint if you live in social housing.

On page 16 our Services Director for Information Services, Gill Bird, talks more about DSA FuturesTM,

a brand-new DSA programme that bridges education and our DSA WorkFit[®] programme, which we are very excited about.

You can read more about WorkFit on page 23 in a piece about James and Joe's experience of working at Royal Mail.

As usual our member stories are just brilliant and showcase wonderful lives and experiences. I remember our cover star Daniel Barnes on the front of that old magazine! So do keep sharing your stories with us.

I am happy to report that My Perspective 2024 was a huge success and would like to thank everyone who participated. The 2025 competition is now open, so get involved!

We have a huge range of training and support on offer in the coming months which are all highlighted in our DSA news section, so do check those out.

Please continue to share your feedback with us which helps to inform our work and the support we can offer to you.

Carol Boys OBE
Chief Executive

WELCOME

Letter from Kate Powell



Welcome to the Journal.

At this time of year, we are looking forward to spring and all the promises it brings. In the same way, I am looking forward to reading about all your experiences and achievements in the Journal. They are so inspiring to me.

I was lucky enough to be invited to this year's My Perspective photography competition awards evening and exhibition, and saw the winners presented with their prizes. The whole evening was outstanding.

After four years I have stood down as a UK ambassador for the DSI. It was a great experience talking to ambassadors from all over the world. I shall miss our monthly Zoom meetings. I would like to thank Robin, Nathan and Chris for their help and support.

Lastly, I would like to give my congratulations to our CEO Carol Boys for being awarded an OBE in the King's Birthday Honours List.

Stay safe everyone,

Kate Powell

DSA NEWS

Carol's Investiture	4
What's Going on at the DSA?	4
Coming Up and Coming Soon Helpline	5
New Resources	5
My Perspective 2025	6
Ambassador and Patron Update	6
Portrait of Britain Awards	6
Leaving a Legacy	7

HEALTH

Epilepsy and Seizures	8
-----------------------	---

SUPPORT

Complex Needs	11
Early Support	12

POLICY

Policy Update	13
---------------	----

HOUSING

Housing: What are the Options?	14
Sam's Story	15
Know How To Complain	15

EDUCATION

DSA Futures - A New DSA Programme	16
-----------------------------------	----

OUR VOICE

Our Voice Update	18
About Me	18
Inclusion Advisors' Update	19

DSACTIVE/DSENGAGE

DSActive/DSEngage Programme	20
-----------------------------	----

WORKFIT

Employee Spotlight	23
An Incredible Milestone	23
What We've Been Up To	24

FUNDRAISING

Fundraising Events	25
Lottery	25

CORPORATE

Partnership with Big Yellow Foundation	26
----------------------------------------	----

OUR MEMBERS

Dance to me is a Driving Force	27
JJ's Trip to Paris and Disneyland	28
James and the Wacky Woodpeckers!	29
Tanzie: H&M Awards	30
Abby's Wedding	31
Cover Star!	31



CAROL'S Investiture

We are thrilled to share this photo of Carol Boys, our Chief Executive, with her OBE at Buckingham Palace.

Carol received the honour from His Majesty King Charles III at a ceremony just before Christmas, after being included on the King's Birthday Honours List, in recognition of services for Special Educational Needs and Disabilities and to Research, in June last year.

WHAT'S GOING ON AT THE DSA?

We offer free training to support individuals at every stage of their lives, from 'Tell It Right' training for maternity professionals, to online training, lunchtime webinars for professionals delivered by health experts, workshops and parent carer meetings.

Subjects covered include early years support, transition to adulthood, education and development, speech, language and communication, positive behaviour support, adolescence and puberty, complex needs and autism, employment, support for adults and ageing and dementia.

Contact training@downs-syndrome.org.uk to find out more about our training services.

View what's on and register for our live online training and regular parent/carer support meetings via our Training and Support page on our website: downs-syndrome.org.uk/our-work/services-projects/training

COMING UP



Supporting people with a dual diagnosis of Down's syndrome and autism

Supporting People with a Dual Diagnosis of Down's Syndrome and Autism

Thursday 27 March 2025
10 – 11.30am | FREE

This is the second of two webinars on dual diagnosis. This webinar is aimed at those who are awaiting or have received a diagnosis of autism.

A recorded version of the session will be available after the training session, for a week, for those who sign up for this online workshop.



Tell it Right Webinar for Maternity Services and Universities

Tell it Right® Webinar for Maternity Services and Universities

On-demand webinar | FREE

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.

Early Reading Strategies to Support Speech and Language Development

Thursday 22 May, Thursday 5 June and Thursday 19 June | 1.30 -2.30pm | FREE

COMING SOON



Early Years and Primary Education online training workshop

Early Years and Primary Education

This new, co-produced, 90-minute online training session for education practitioners and parents explains how to support learners who have Down's syndrome from four to 11 years of age in education settings.

It will include recommendations for social inclusion and curriculum access, speech, language and communication and social development.

- Relationship and sex education
- Dementia and ageing
- DSA Futures™

- Understanding and supporting behaviour change in children
- Sensory processing awareness

HELPLINE

Our helpline is a unique service.

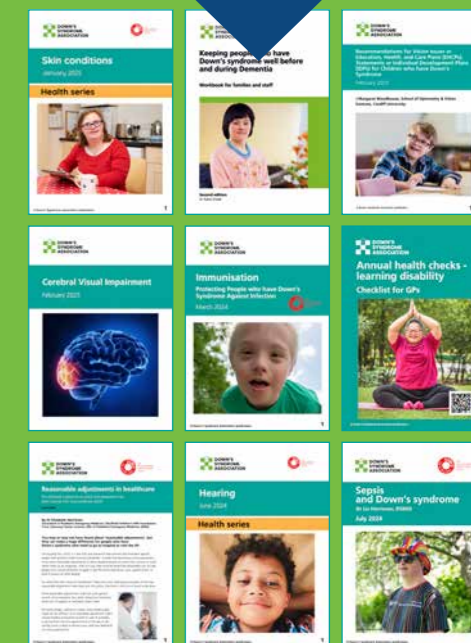
We are the only helpline that anyone can contact on all areas related to Down's syndrome. Our knowledgeable Information Team will answer questions on any topic that arises throughout the whole lifespan of a person who has Down's syndrome.



NEW RESOURCES

We have several new fantastic resources now available for download from our website:

downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/



We recently promoted and published a helpful blog on money management, containing some useful resources and tools to help support decision-making and financial independence. If you missed it, you can read it here:

downs-syndrome.org.uk/news/resources-information-training/information/money-management-for-adults-who-have-downs-syndrome/

We are also busy building professional networks and will be attending the RCPCH (The Royal College of Paediatrics and Child Health) 2025 Conference in Glasgow later this month and we continue to work closely with the Integrated Care Boards.



My Perspective
2025
MY PERSPECTIVE
DOWN'S SYNDROME ASSOCIATION

Shaishav Singh - Finalist, 2024

Focusing solely on photography this year, My Perspective 2025 is now open for entries.

Help us to celebrate and share your view of the world; get involved!

downs-syndrome.org.uk/MyPerspective

AMBASSADOR AND PATRON UPDATE:



Iris

Last year Ambassador Iris ran the Cardiff half-marathon for us and raised £250.

In May, she'll be taking on the Edinburgh Marathon to add to her incredible DSA fundraising to date.

Thank you so much Iris!



Image courtesy of Aaron Fitzmaurice

Aitch

DSA's Ambassador Aitch took on the challenge of a lifetime, climbing and summiting Kilimanjaro in January to raise money for the DSA.

Absolutely incredible effort, thank you Aitch!



PORTRAIT of Britain Awards



We would like to extend huge congratulations to long time DSA supporter and My Perspective photographic consultant, Rory Langdon-Down, who is a winner in the 2024 Portrait of Britain Awards, for his fabulous photo of Woody.

Woody is from London and plays football for the Brentford Penguins.

Find out more about Rory's work here:

rorylangdondown.co.uk
@rorylangdondown



LEAVING A LEGACY

Please do something today that will give us all a brighter tomorrow

GIFTS IN WILL

As a supporter of the Down's Syndrome Association, you help keep us going each and every day.

Leaving us a gift in your will is invaluable. It allows us to plan for the future, enabling us to continue our work of providing the support and services people who have Down's syndrome need to live full and rewarding lives.

How Your Gift Will Help



You will keep our vital helpline open where people get expert and confidential support, referrals and assessments.



You will support our training programmes so that people who have Down's syndrome can get the expert help they need.



You will fund our DSAActive/DSEngage programme that provides opportunities for people who have Down's syndrome to lead healthy, active lives.



You will also help us continue to campaign for the rights of people who have Down's syndrome.

A Simple Guide to Leaving a Gift in your Will

There are three types of legacy:

Residuary Legacy

A gift of the remainder of your estate once all gifts and expenses have been made ensuring your loved ones are provided for.

Pecuniary Legacy

A gift of a specific sum of money.

Specific Legacy

A gift of a named item, for example, jewellery or property.

Making or amending your will is normally very simple and a solicitor can arrange it quickly and easily.

It's worth remembering that there may be inheritance tax advantages to leaving a charitable donation in your will.

Your will writer will need the following information:

Down's Syndrome Association – Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex, TW11 9PS, Registered Charity Number 1061474

Get in touch

If you would like any further information, or have any questions, please do get in touch with our Fundraising Team.

You do not need to tell us if you intend to leave us a gift in your will. However, we are extremely grateful for any gifts that you can leave us, and we would love to thank you personally.

0333 1212 300

email info@downs-syndrome.org.uk

'When my son was born, I had no idea where to turn. I would say to parents, go to the DSA ask them the questions that you really want to know the answer to.

It is a dynamic association, advocating, researching, improving the lives of people who have Down's syndrome on a personal level but also on a national one.' (Parent)

EPILEPSY and Seizures



By Dr Liz Herrievan, DSMIG
(Down Syndrome Medical Interest Group)



People who have Down's syndrome are more likely to develop epilepsy in their lifetime than people in the general population.

About Epilepsy

What is Epilepsy?

Epilepsy is a neurological condition that causes seizures, or abnormal movements, sensations or behaviours. It is more common in people who have Down's syndrome.

Around one in every 10 people who have Down's syndrome will develop epilepsy at some point in their lives, compared to around one in every 100 people who do not have Down's syndrome.

Seizures are caused by abnormal electrical activity in the brain, which temporarily affects how the brain works. Seizures may involve part or all of the body and can look like jerking or twitching movements, lip smacking, the body becoming suddenly floppy, or becoming very stiff.

Some seizures don't involve movements, but the person may feel something strange, may become 'absent' for a period (e.g. staring or unresponsive) or may behave strangely. Sometimes a person may be aware they are having a seizure (e.g. if the seizure just involves their hand) but more often people are unaware they are having a seizure (e.g. if the seizure involves the whole body or is an absence seizure). Seizures affecting the whole body are called generalised seizures. Seizures affecting a part of the body are called focal seizures.

More information can be found here:

[nhs.uk/conditions/epilepsy/](https://www.nhs.uk/conditions/epilepsy/)

What to do if Someone is having a Seizure

If someone is having a generalised seizure or has lost consciousness lay them or roll them onto their side.

- Move things away from them so they do not hurt themselves.
- Do not put anything in their mouth.
- Cushion their head if they are on the ground.
- Loosen any tight clothing around their neck.
- Stay with them and reassure them.

Call 999 for an ambulance if it is their first seizure, if there is anything abnormal or if you are unsure. Most people who have epilepsy do not need to go to hospital if they have a seizure which is a usual type of seizure for them.

Tests for Epilepsy

Anyone having their first seizure, a longer seizure than usual, or an abnormal seizure for them should see a doctor urgently.

If you suspect someone may be having seizures, it can be useful to video them, to show a doctor what it looks like. A diary of when the abnormal movements or behaviours happen, what they look like, any colour changes or noises, what had been

happening just before, and how long they last can also be useful.

An EEG (electroencephalogram) can help to diagnose epilepsy. About 20 electrodes are attached to the scalp to record electrical activity in the brain. This does not hurt, but some people may get distressed by the feel of the sensors. The sensors are left on for about 20 minutes (sometimes longer).

Reasonable adjustments should be made (and are required by law) to enable a person who has Down's syndrome, who is anxious or who does not understand what is happening, to tolerate the test.

This may include some time to get used to the sensors, having a longer appointment, or using social stories or pictures in advance. A learning disability nurse can be really helpful with this.

More information can be found here:

[nhs.uk/conditions/electroencephalogram/](https://www.nhs.uk/conditions/electroencephalogram/)



A CT scan of the head may be carried out. This test is usually pretty quick to do but still requires someone to stay still for a few minutes. The person will be asked to lay on a bed which moves in and out of the scanner, which itself is shaped like a large Polo Mint or doughnut. It can sound a bit like a washing machine and the room is often cool. The machine does not touch the person. The bed moves in and out of the scanner a couple of times. If needed, VELCRO® straps and cushions can be used to help the person feel comfortable and safe as the bed moves.

Again, reasonable adjustments may be used, such as a longer appointment, time to get used to the room and bed, pictures of the room beforehand and, if appropriate, sedative medications.

An MRI scan gives more detail than a CT scan but is more difficult to tolerate and carry out. The person must lay on a bed which moves into the MRI machine. The machine is like a tunnel, and the sides are very close to the person. It is very noisy, with lots of banging, beeping and whirring noises. Headphones can be worn with music to listen to, along with an eye mask if needed. It can take a long time (an hour is not unusual).

Very strong magnets are used, so the person must have no metal on them. Any metal in the body (e.g. following surgery) is often safe for MRI scanning, but you must tell the MRI team about it so they can check. As the scan is difficult for many people to tolerate, sedation or even a general anaesthetic may be used, if the benefits of this outweigh the risks.

Blood tests are sometimes useful when investigating seizures, including full blood count, liver function, kidney function, glucose, calcium and magnesium.

An ECG is usually carried out to look for any cardiac (heart) causes of collapse which might look like a seizure.

Infantile Spasms

This is a form of epilepsy which usually occurs in children under one year of age and is more common in babies who have Down's syndrome than in other children. Other names include West Syndrome and Epileptic Spasms. These usually start at around three to six months of age. Almost half of all people who have Down's syndrome

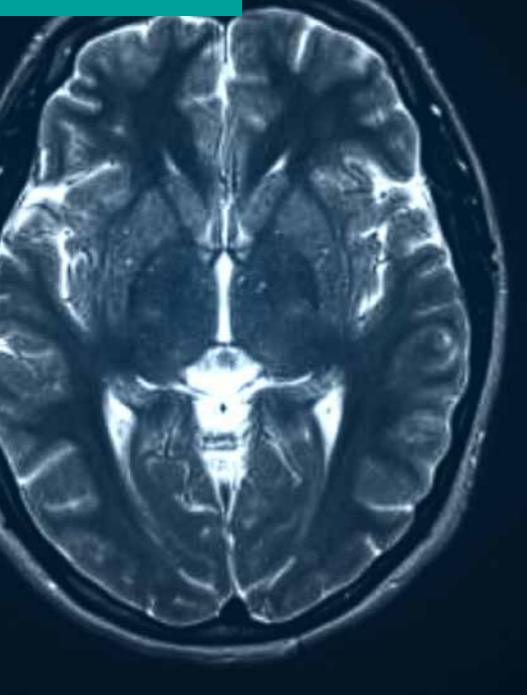
who develop epilepsy will have infantile spasms.

Families may notice that the child's head suddenly nods forwards. Sometimes the arms or legs will also move quickly (a jerk, twitch or exaggerated shrug) and the child may become upset. The movements are very brief (lasting less than a second) but may occur in 'clusters' where several of these movements occur close together. The child's development may also appear to slow or regress at around the same time.

The sooner treatment is started, the better. Treatment may include steroid medication, or a medication called vigabatrin.

Some children with infantile spasms will recover fully, having no further seizures and no additional problems with their development after treatment is started. Some children will continue to have seizures as they grow older. The seizures seen in these children may look different to the spasms that they had when they were babies.





Some children with infantile spasms may go into 'remission' when the seizures stop, but sometimes the seizures will then restart. Any of these scenarios may occur in a child who has Down's syndrome, but in many cases the response to treatment is good, the spasms disappear quickly with treatment, and the seizures do not recur.

Children who do not have Down's syndrome, who develop infantile spasms, often go on to have problems with their development and a long-term learning disability. Children who have Down's syndrome will already be expected to have some degree of learning disability.

Other things that cause sudden movements in babies, which may look like infantile spasms, include reflux, an exaggerated (but normal) startle reflex and benign infantile myoclonus. If unsure, it is important to seek medical advice.

Febrile Seizures

Febrile seizures, or febrile convulsions, occur in children aged six months to five years, in response to a sudden increase in temperature, usually during an infection. A wide range of infections can lead to febrile seizures, including viral illnesses as well as bacterial infections. A febrile seizure involves loss of consciousness with jerking or twitching of the head, neck,

arms and legs. The child is usually hot to touch.

Febrile seizures are usually brief, stop by themselves and, although very scary to watch, cause no long-term problems. Most children who have a febrile seizure will have just one, although some may go on to have others.

If a child has a febrile seizure, the seizure advice above should be followed.

If a febrile seizure lasts more than five minutes, medications are given by the ambulance crew or by hospital staff to stop the seizure. Hospital staff will also look for the cause of the infection. After a febrile seizure, the child is usually sleepy or irritable for a while and may take some time to get back to normal.

Febrile seizures cannot be prevented, even by giving regular medications to bring down a temperature.

A small number of children who have febrile seizures will go on to develop epilepsy, but most will not.

More information can be found here:

nhs.uk/conditions/febrile-seizures

Late-Onset Epilepsy

After infantile spasms, the next most common type of epilepsy in people who have Down's syndrome develops at around 40 years of age. It may involve generalised seizures, with repetitive jerking or twitching of the whole body, or myoclonic seizures, which are sudden, involuntary shock-like movements of one part of, or the whole of, the body.

Late-onset epilepsy is often related to the development of Alzheimer's disease in people who have Down's syndrome and there may be a decline in abilities at around the same time. Anti-epileptic medications help to control seizures.

Other Types of Epilepsy

Over 40% of those who have Down's syndrome who develop epilepsy have infantile spasms. Another 40% develop late-onset epilepsy. The rest develop seizures at other points of life, with a variety of types of seizure. Treatment

is the same as for people who do not have Down's syndrome, with anti-epileptic medications (although there is some evidence that the medication phenytoin causes more side effects in people who have Down's syndrome than it does in other people). It can sometimes take a while to find the most suitable medication for an individual person, and the most appropriate dose.

Seizure Safety

Seizures can put people at increased risk of injury and harm, so there are some important safety points to remember:

- Keep wires and cables out of the way, to avoid pulling equipment over.
- Use guards on heaters and radiators to avoid injury if a person falls on them.
- Consider having cushioned flooring such as carpets or linoleum instead of hard flooring.
- Cover furniture edges and corners that stick out and may cause injury.
- Avoid locking the bathroom door when having a bath (an 'engaged' or 'in use' sign could be used instead) and always make sure someone knows when the person with epilepsy is having a bath. Have showers instead, where possible.
- ID cards, to tell first-aiders that a person has epilepsy, can be useful when out and about.
- Activities such as swimming or cycling may be safer if the person is accompanied by someone who knows what to do if a seizure occurs.

We would like to draw your attention to information at this link about Annual Health Checks, Reasonable Adjustments and the Learning Disability Register:

downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/

Dr Liz Herrievan (DSMIG UK & Ireland)
Publication date: 2025

The above is available as a downloadable resource from our website:

downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/epilepsy/

COMPLEX NEEDS

Update



By Stuart Mills and Jane Mitchell



In-Person Support Meeting

In September 2024 we hosted our second parent support meeting in Manchester. We enjoyed another day of sharing experiences, learning and looking after ourselves.

We are happy to announce a further parent support meeting in London in June this year. You can find the details on our **Training and Support** and **Complex Needs** webpages.

Online Meetings

These continue to happen approximately every six weeks, and over the last few months the attendees have discussed such topics as:

- communication
- inclusion
- dual diagnosis of autism.

Our online groups are always warm and friendly, where people talk openly, honestly and feel supported. We welcome new members, as well as returners.

Future Dates for Online Meetings in 2025

- Thursday 1 May
- Thursday 12 June

All meetings run from 10.30am – midday.

To attend please book via our **Training and Support** or **Complex Needs** webpages.

Our webpage also offers a fantastic series from parents called Top Tips which gives advice on Christmas, going on holiday, attending a health appointment and arranging an event.

You can also visit our complex needs Facebook group for further support.



Regression – Rapid Loss of Skills

Some people who have Down's syndrome experience a rapid loss of previously acquired skills (ability to do activities, language and communication, motor function and social interaction) when in adolescence or early adulthood.

The changes seem to happen quickly (unlike dementia where the changes are slow) over days or weeks.

For many years the DSA has been aware of, and concerned about, the numbers of people who have Down's syndrome and regression.

We continue to listen to families who are affected by this condition, and in response have developed resources for information and advice. In October we held our first parent support group.

We also have a dedicated page for regression on our website, where we share research, updates and parent stories.



Our next regression parent support group is scheduled for 17 June, 10.30-11.45am. So do keep an eye on our website for registration details.

Please visit our **Complex Needs** webpage and Facebook page for more information and support:

downs-syndrome.org.uk/ComplexNeeds
facebook.com/groups/DSAComplexNeeds



Group by Down's Syndrome Association

Regression in Down's syndrome (UK)

Private group · 205 members



+ Invite

Share



Let us know your thoughts; are there other health issues or areas you would like us to cover?

EARLY SUPPORT

Our DSA Pregnancy and Baby Support Group continues to support parent/carers of babies up to 18 months of age as well as expectant parents looking forward to welcoming their baby.

The group offers a warm, safe space, and the opportunity to meet other parents. Members of the DSA team are on hand to answer any questions on any topic.

Our speech and language therapist will join sessions to talk about feeding and weaning and early communication and our occupational therapist will talk about early physical development. We will also have an introduction to Makaton.

I am not sure who has enjoyed the group more, me or Matilda. She lights up whenever we join the call and was keen to join the conversation today. She clearly knows a good group of people when she sees one...

I am so grateful to everybody involved in the support group. Not only have you provided a wealth of helpful information and resources, but also reassurance, kindness and access to a new community. It has been a difficult eight months, and these calls have made an enormous difference to our family.

You've helped empower me to look after and out for Matilda, and that is something I will always be grateful for. Hopefully we will see you in future groups!

Francesca Hawkins Jette, parent to Matilda who attended the DSA Pregnancy and Baby Support Group in October 2024.

The DSA Early Communication and Development Support Group started last year and is for parent/carers of babies from 18 months up to 3 years of age.

The sessions cover information on early communication, early development and play and an introduction to Makaton, and follow on from the Pregnancy and Baby group, helping parents access continuing support throughout their child's early development.

'I am so grateful the DSA offers this group. It has been amazing to have their constant support and guidance. Lots of different activities and strategies shared on communication, development and play. Thanks so much for walking with me throughout the first two years of my little one and making me feel I was never alone on the journey.'



Miryam Chiner, parent to Gonzalo who is 2 years old and attended DSA Early Communication and Development Support Group sessions in October 2024.



A new support group will be starting in May this year.

The **DSA Early Reading Strategies Group**, to support speech and language development, will meet for three fortnightly sessions from 1.30-2.30pm on 22 May, 5 June and 19 June. We look forward to meeting parents and practitioners who would like to come along to the group. Visit our Training page or email training@downs-syndrome.org.uk to find out more.

POLICY

Update



By Sharon Smith,
Head of Marketing and Strategic Communications

The last few months have been incredibly busy from a policy perspective.

Following the summer recess, the new government has initiated several consultations aimed at addressing issues relating to Special Educational Needs & Disability (SEND), health and social care.

We have engaged in consultations/inquiries relating to both children's and Adult's social care, community and school sport, employment, modernisation of Parliament, health and education.

This has kept the DSA team busy, as we've been actively participating in these consultations, often several concurrently, and teaming up with other organisations on various initiatives.

Significant pieces of work include:

Curriculum and Assessment Review (CAR)

In July 2024, the government launched the UK Curriculum and Assessment Review, chaired by Professor Becky Francis CBE who is the CEO of the Education Endowment Foundation and an expert in education policy. The Review board includes a diverse group of experts from various fields, including Gary Aubin who is leading on SEND engagement.

We held an online webinar to share information about the Review, featuring Philippa Stobbs, a well-respected SEND advocate who recently retired from the Council for Disabled Children after three decades of dedicated service, and Gary Aubin from the Review panel. We also conducted a survey to gather input from our members to inform our response to the consultation, which also drew on feedback from DSA Our Voice members.

Our response to the Review drew attention to the need to have an inclusive ethos and high expectations for learners who have Down's syndrome, the importance of having a curriculum which considers learners

with SEND from the very start rather than an 'add on' and inclusive assessment and qualifications, allowing all learners to have a sense of achievement and progression. We highlighted issues relating to a lack of suitable support and adaptation for some learners who have Down's syndrome, and how a lack of suitable progress measures, combined with deficit-based language in reporting, can lead to a continual sense of 'falling behind', even when significant progress has been made.

One parent shared that it's crucial to ensure that *'those who can access GCSEs are encouraged to do so, and to have clear alternative skills qualifications available in mainstream schools and colleges, so those students who want to learn there can follow a meaningful and progressive skills and development pathway and not be left sidelined.'*

Change NHS

Launched in October 2024, the "Change NHS" consultation is part of the UK government's initiative to build a health service fit for the future. It aims to develop a 10-year health plan through public and staff engagement. The goal is to create a modern, responsive NHS that meets the changing needs of the population.

During November and December, we ran a short communications campaign to encourage members to engage in the consultation process via the Change NHS Online portal. We also worked with members of Our Voice to inform our own organisational response. In this response we highlighted issues relating to the need for accessible information, Learning Disability Annual Health Checks, transition between services, the need for appropriate diagnosis and support relating to dementia, and reasonable adjustments when engaging in the health system.

Our Voice members told us *'They could improve communication and information – they need to make sure they are talking to the person who has a learning disability.'*

Down Syndrome Act 2022

The DSA continues to engage with the team working on the development of the Guidance related to the Down Syndrome Act 2022. There has been an assurance by Stephen Kinnock MP that the Guidance will be published for wider public consultation in early 2025.

We will provide information and opportunities to engage in the consultation process when more details are available.

What's Next?

At the time of writing, we are working on our response to the Law Commission Inquiry relating to children's social care, the Education Select Committee's inquiry 'Solving the SEND Crisis' and a consultation by the Welsh government relating to post-16 education provision. We know that there will be further policy work in the coming months relating to the 'Get Britain Working' white paper, which was published in November 2024. We look forward to being able to share the successes of the DSA WorkFit® programme as part of our engagement in this work.

As always, keep an eye on our website, newsletters and social media for news of our policy work and opportunities to have your say.

If any members would like any information on, or to discuss further, any national policy issues please do reach out to us at policy@downs-syndrome.org.uk

HOUSING:

What are the Options?

By Chris Watson, DSA Adult Social Care Advisor

Exploring Housing Options for People who have Down's Syndrome

Finding the right place to live is a key step in building independence and security for people who have Down's syndrome. There are many housing options available, each with its own benefits and challenges. Understanding these choices can help families and individuals find the best fit for their needs and aspirations. We have listed a few of the main options available below:

Private Renting

Renting privately means leasing a home from a landlord. This option offers flexibility in choosing where to live and the type of property. For example, you might opt for a flat close to work or a house near family. However, private renting can be expensive, and leases may only last a year or two before needing renewal. Families often help manage the relationship with landlords to ensure a stable living arrangement. It's worth exploring housing benefit eligibility to help with costs.

Social Housing

Social housing is managed by councils or housing associations and is often more affordable than private renting. It provides secure tenancies, which means tenants are less likely to face sudden moves. The challenge is that demand for social housing is high, and waiting lists can be long. To improve your chances, register early and provide detailed information about support needs. Many families find that working closely with social work teams helps to prioritise applications.

Shared Ownership through HOLD: A Home for Life

For individuals with long-term disabilities, the HOLD (Home Ownership for People with Long-term Disabilities) scheme, managed by My Safe Home, offers a unique opportunity to secure a home for life. HOLD allows eligible individuals to buy a share in a property that meets their specific needs while

using housing-related benefits, such as housing benefit, to help cover the rent and service charges on the unsold portion. This scheme provides not just a financial solution but also the reassurance of long-term stability and independence. Unlike traditional shared ownership, HOLD is designed to offer a home tailored to an individual's circumstances, ensuring it can accommodate their needs throughout their life.

Buying with Family Help

Families may choose to purchase a property outright or invest jointly with their loved one. This can provide long-term stability and ensure the home meets specific needs. For example, families can make adaptations like adding grab rails or creating wheelchair-accessible spaces. However, it's essential to think about long-term plans, such as who will manage the property in the future and consider legal arrangements like discretionary trusts.

Supported Living

Supported living offers a balance between independence and support. Individuals can live in their own flat or a shared house with others, receiving tailored help to meet their needs. Support might include assistance with cooking, cleaning, managing money, getting to and from work, or attending appointments.

For example, someone might live in a flat with staff available on-site for help when needed, but they can still lead their own life. Supported living encourages independence while ensuring safety and support. Families often find this option ideal because it allows their loved one to take control of their daily routine. Local charities and care providers often have information about supported living schemes in your area.

Shared Lives Schemes

Shared Lives involves living with a carer or host family. The person who has Down's syndrome becomes part



SAM'S STORY



Sam unpacking in his new place

Firstly, could you please tell us a bit about yourself, where you live, who do you live with, how old you are etc.

My name is Samuel Searle and I'm 35 years old; I live in Southampton close to my parents and my two sisters. I have lived in Southampton all of my life.

Tell us how you came to get your own place?

I have been living in a house that is known as supported living with one other man. Carers would come into the house and help us prepare our meals. I was renting in this house from a housing association within an ordinary Assured Shorthold Tenancy Agreement (AST). The landlord could have given me 56 days' notice to move out without any reason. I know that this has happened to others in Southampton. I asked my parents to see if we could buy a flat for me, I noticed that my sisters were buying their own places and they were making the places their own, decorating and things.

How do you feel about having your own place?

I like having my own place as I'm away from mum and dad. I have my own ensuite bathroom with my bedroom which is at the front of the property. I like to be at the front so I can see when people arrive and leave.

Why is it important to you to have your own place?

I wanted to try and build a little security into where I live, and I thought by owning a property this might help me and my family have more control of this.

What is the best bit about having your own place?

I control what I watch on TV, when I play my games consoles and when I wake up and go to bed. I have my own key.

What is the worst bit?

Sometimes I can feel lonely, although I know I can always video call mum or dad.

Is there anything else you would like to share with us and our readers?

My mum, dad, two sisters and my social worker have helped a lot with purchasing my own home. Dad did a lot of research and kept me informed of the process. We did face a few obstacles along the way, but dad spoke with other organisations to seek advice and support.

of the family's day-to-day life, sharing meals and activities while receiving the support they need. This option is highly personalised and works well for individuals who enjoy being part of a close-knit household. Shared Lives schemes are typically arranged through local authorities or specialist care provider organisations.

Residential Care

Residential care homes are generally designed for people with higher support needs. They provide 24-hour care in a structured environment, ensuring that all medical, personal, and social needs are met. While residential care offers accommodation and comprehensive support, it can feel less independent and more restrictive and regimented compared to other options.

Intentional Communities

These are housing arrangements where people with similar experiences live and work together in a supportive environment. These communities often include shared spaces for meals and activities, fostering a strong sense of belonging. For example, some communities involve farming, gardening or craft workshops that residents can take part in. This option is ideal for individuals who value social connection and enjoy group activities. However, it's worth considering how much privacy and independence the individual wants, as community living can be more structured than other options.

Finding the right housing can take time and effort, but there's help available. Local housing advisors and social work teams should be able to provide you with practical support and guidance.

If you're unsure about where to start, reaching out to social services is generally the first step. They're there to help you find a home where you or your loved one can feel safe, happy, and supported.

The Down's Syndrome Association also has a Social Care Advisor who can provide guidance around housing too, please contact our helpline for more information if you would like to book a chat. **Helpline: 0333 1212 300. Call between 10am and 4pm.**

Social Housing Issue? Know How to Complain

If you have a disability, you are more likely to live in social housing and sometimes you may have problems with your home. You may even have sleepless nights about the issue. Knowing how to complain is the key to making things right.

If you or somebody you know lives in social housing, your landlord is your first point of contact to deal with your issue. They are responsible for fixing issues including damp and mould, broken locks, or changes you need to your home if you are disabled. They can also help with anti-social behaviour, like noisy neighbours.

There are three steps to complaining. By following them, you have the best chance of getting your problem fixed.

Know the three steps to complain.

Step 1. Report it to Your Landlord

First, report the issue to your landlord. This is who you pay your rent to – it could be your local council or a housing association. Most landlords will have a website with a report form to fill in. If not, you can still report your issue using their email or phone number.

Be reassured, landlords are there to deal with your problem, so always report it.

Step 2. Complain to Your Landlord

If you've reported an issue and you feel it's not properly sorted, complain to your landlord. Remember, you have a right to complain if you're not happy. Your landlord will explain how to complain on their website.

When you make a complaint to your landlord about a problem that has not been fixed, they are legally required to respond to issues fairly and effectively. Your landlord should explain the complaints process and how long it will take. Landlords must take your complaint seriously and cannot punish you in any way for raising a problem or making a complaint.

Landlords have 2 stages to their complaints process.

Stage 1: They must get back to you within **10 working days** from the day you logged your complaint.

Stage 2: If your complaint still hasn't been resolved, it can go to stage 2. Landlords must respond within

20 working days. They will send you a final response, which may explain how they plan to fix things.

Step 3. Escalate to the Housing Ombudsman

If you're still not happy with what your landlord says in their final response to a complaint, you can tell the Housing Ombudsman.

The Housing Ombudsman looks into complaints about social housing and landlords.

They are free to use and investigate your problem fairly.

If the Housing Ombudsman tells your landlord they have made a mistake, the landlord **must** show they have a plan to fix things within six to eight weeks.

Last year, the Housing Ombudsman ordered landlords to pay over six million pounds to people who had problems in their homes. You can contact the Housing Ombudsman here:

- Online form: housing-ombudsman.org.uk/residents/bring-your-complaint-to-the-housing-ombudsman/
- Email: info@housing-ombudsman.org.uk
- Telephone: 0300 111 3000

Remember, follow the **3-step process**, and know your rights.

You can find out more at gov.uk/social-housing



You can find our Easy Read version of **Social Housing Issue? Know how to complain** here: downs-syndrome.org.uk/easy-read-information



DSA FUTURES

A New DSA Programme

DSA Futures™ is an exciting new programme that bridges the gap between education and living the life you want.

The programme aims to support all people who have Down's syndrome, aged 14-25 years, as they prepare for their futures. Discover options for personal progression (whatever that looks like), meaningful activities in adulthood and employment opportunities.*

Although we would like to see more young people who have Down's syndrome leave formal education ready to take advantage of the employment opportunities available via the DSA WorkFit® programme, DSA Futures is not just about a bridge to work but is about ensuring that everyone aged 14 onwards is provided with opportunities to live meaningful lives that they choose. This should include a range of options to choose from including high quality specialist provision when appropriate.

We are launching the programme with publication of a comprehensive transition resource that sets out a timeline with actions for every stage from 14 years to adulthood**, and with a series of fortnightly DSA Futures online sessions for parents and carers of young people 14 – 25 years and practitioners who are part of the process across this period. The topics include health and well-being, further education, employment, finance, relationships and sex education, legal frameworks for decision making, housing options and social care planning.

To help inform the shape of the support, resources and training services that DSA Futures will offer, we will gather information about the issues that enable and limit people's opportunities through engagement with stakeholder groups. We will seek out innovative post-16 education practices, including for young people who have complex needs. We will explore what knowledge and information parents and carers need to effectively support their young people as they move towards adulthood.

In addition we will be researching the experiences of learners, aged 14-25 years, in relation to their options for development, to identify what has helped them.

Starting Early at School and College

For successful outcomes in finding a wide range of meaningful activities as adults, the journey must start at school and/or college. Schools and colleges have the unique position of being able to foster and encourage a positive and aspirational presumption of future activities among learners who have Down's syndrome and their families, including around employment opportunities. Sadly, this does not always happen. Schools and colleges

can have low expectations and provide limited choices for people who have Down's syndrome.

We know it is difficult for learners who have Down's syndrome to access inclusive college courses and vocational pathways of their choosing. There are a limited number of qualifications and courses that are generally available to learners who have Down's syndrome. These frequently tend to focus on life skills, animal care, health and social care, hospitality or performing arts, although learners who have Down's syndrome have a wide range of interests and aspirations.

Parents and carers tell us that support in formal training/preparation for work is few and far between. Some feel that just talking to individuals about what jobs might involve is not enough. Practical experience is needed to really give learners that context.

We want to ensure more young people who have Down's syndrome, who are leaving education, have transferrable skills and knowledge that can be used to approach employment in a variety of roles and settings. This then gives them choices from a range of opportunities within any organisation.

Local mainstream and specialist schools and colleges must therefore start talking to students about working towards possible career options early. They should also be expected to source high quality, well supported work experience/taster sessions within and beyond the traditional sectors of retail, catering and hospitality. Schools and colleges should be liaising with employers and activity providers so that they can offer support with short-term taster sessions in a variety of locations and settings. Travel training should be provided too, which will enable more young people to be able to travel confidently in the future.

Due to the lack of choice and aspiration locally, some families will choose for their young person to attend a specialist residential college. Residential colleges may offer specialist vocational courses that are not available at local colleges, as well as opportunities to develop independence skills and confidence. These are often many miles from home and take the young person



out of their local community. There are also very limited spaces in such residential colleges, meaning that most young people who have Down's syndrome will not have the same exposure to education focused on developing skills and knowledge that will maximise their opportunities for their futures, after their formal education has been completed.

Building on the knowledge gained, the DSA Futures programme (practical support, best practice guidance, co-produced information/resources and training) will be developed, importantly this will all be co-produced with young people who have Down's syndrome.

What do young people who have Down's syndrome say about work opportunities?

'As an adult I would like to find a job that I would like to do. For example, I would love to work with younger children but there's not many jobs, which bugs me. All the jobs are animal care, beauty, and hairdressing and those don't suit me.' (Harshi)

'I did work experience at a shop, where I tagged the clothes and counted money. At my college there was a special house where you go to practice ironing, hoovering and cooking.' (Samuel)

'I normally do catering but I also help in school. If you are over 18 having to find a job is a challenge. I also remember learning to travel to college on my own. I did a catering course during my college course. I can't remember much about it, but I do remember doing work experience at different restaurants and an office. It was useful.' (Molly)

*Employment opportunities include paid work, volunteering, work experience, supported apprenticeships and internships.

** Initially this applies to England only. We will shortly be producing versions for Wales and Northern Ireland.

OUR VOICE UPDATE

By Bethan, Claire, Lorni, Andy, Tanzie, Jenny, Harshi and David

Our Voice is the DSA's self-advocacy group for teenagers and adults who have Down's syndrome. We speak up for our rights, help the DSA with their work, and socialise together. This is what we think about the group:

Our Voice is a nice thing, we like doing it, we see our friends. We like to speak up for our rights in different ways.

It's happy and good.

We have been here since the beginning and it's nice to have seen the progression of Our Voice. It feels like this is our friends and our family. Everything that we have done on Our Voice is amazing and we are glad we found it. It's an amazing experience.

We have grown so much through Our Voice; we think it's fantastic to join. It's a really good challenge, what we do. It feels like Our Voice is a part of our life and we think we do a fantastic job of getting people with learning disabilities to help people who have Down's syndrome get included. It helps people speak up for themselves more in a community.

It helps us learn about different topics, it's nice to see different people on Our Voice. It makes us happy because Our Voice treat us like family. We miss Robin being part of the Our Voice family.

It's thanks to Our Voice starting up that we got to say how we felt. It was in covid lockdowns, so it was nice to have a chance to say how we felt about it all. We get to speak up for our rights. Since it started, we have all have gained confidence, and we can speak up more.

We like meeting new people we like chatting. It feels like a family.

This is some of the work we have done since the last Journal update.

Medical Students

We met with first year medical students at the University of Cambridge. It's good to meet face-to-face on Zoom so they can ask us their questions. We could tell them about our experiences. We can help them be better doctors and see the bigger picture. It helps them learn about Down's syndrome, and it was quite nice.

UK Parliament Week

We watched a short video; it was quite good. Learning about parliament is good it's important to know about talking out loud in front of people. It's important for people who have a disability to vote. It's interesting to know where government sits. There is a battle on the sides! It's a really good reminder of where things are. It's interesting to find out what they've been doing in that area.

DSA Social Media

We can share what we get up to, it's nice to share pictures with friends. It makes us really proud to share the work we are doing with the DSA.

'I shared a mental health poem and an advocacy poem. It makes me feel proud of myself to speak up and to be a changed person.'

'I like being in the Special Olympics and sharing it on social media.'

'I'm happy to share things, and pictures of food! I might make mince pies and share that.'

We like people seeing our pictures – it makes us feel famous. It's fun to share pictures and a bit of info about it.

Relaxed Sessions

We think they're fun. We share news, and it's really nice to hear other people's news. We like playing games in Our Voice, we don't always need to do too much work. It gives us something to do, to focus our brains. We play charades.

We enjoy doing quizzes, like name the logos. Some of us like Pictionary and creative things.



ABOUT ME



Bethan

I'm 43 years old. I like being creative and I like to be active. I do exercise online, like DSEngage

classes, I go to youth clubs and I'm part of Corali Dance Company. In Corali, people with and without disabilities do contemporary dance together and I'm an Office Assistant for them as well. I have been on tour with them for example in Bath, Durham, and Denmark.



Claire

I'm a happy person, I'm independent and I have a sense of humour. I'm also sensible. I like

watching TV, dancing to CDs, and I love yoga. I am in a Signing Choir and I have a paid job as a Life Skills Assistant at Orpheus Centre College. I'm on a number of committees at work, including Health and Safety. I am a big fan of Harry Potter, Call the Midwife and NCIS.



Lorni

I like musicals and Disney, being independent in my flat, Strictly Come Dancing, EastEnders and

Casualty. I like listening to my favourite playlists on Spotify. I don't like spicy food, dark chocolate, olives, spiders or scary films.



Andy

I'm calm, kind and caring. I have one sister called Sarah and I have a niece. I'm into dancing and I

go to college. I do internet café there on Mondays. I volunteer in the office at college every Wednesday, I check everyone's in, in case of fire, and I hand out the name stickers to the support workers. I like football, I support Arsenal and Barnet. I like watching soaps like EastEnders, Coronation Street and Emmerdale.



Tanzie

I am 20 years old. I live with my family and my pets. We have got guinea pigs

called Love and Cuddles, a gerbil called Marshmallow, and two chickens called Daisy and Sophia. I go to two different colleges, and I work on Saturdays at H&M. In my spare time I like colouring, horse riding, swimming and chatting to my friends. I like drama and singing and I am a good friend. I like Disney, Stitch and musicals and sleepovers. I have two coming up.



David

I love watching Power Rangers and Netflix, listening to music, singing

and dancing and going to the cinema. My favourite films are Moana 2, Wicked, Mufasa and Paddington 2. I go to Evolve College and I do dance training at Tin Arts. I like getting books from the library. I am looking forward to going to France with my family to visit the Castle where the Merlin series was filmed and going to Paris to see the Eiffel Tower.



Harshi

I am going to be 21 years old this year. I am currently going to college. My

family tell me that I am funny and cheeky. I have swimming, aquafit and dance lessons. I absolutely love Bollywood Dance. I really enjoy being part of our community such as being in the community choir. I have recently got a paid job with my local authority to train others on how to talk to people who have learning disabilities. I am excited and nervous to start.

Jenny

I volunteer at my old local primary school where I encourage reception class children to read. I am hoping to find more volunteer work through WorkFit and develop my skills. I like horse riding, carriage driving, dancing, and playing board games. I enjoy using a computer and teaching myself sign language. At the DSA I Zoom as part of Our Voice, Pilates and Discos.



INCLUSION ADVISORS' Update

By Catherine and Joe

Since the exciting summer we have continued doing some amazing work.

Things we've been working on:

► Finished all the training materials

We now have a full programme of training on Listen Include Respect. There are modules on the principles of Listen Include Respect, information, communication and good support; also, how to run meetings, consultations and projects. Finally, there is information on leadership and advocacy and campaigns.

► First training session booked in!

We now have our first training with a NHS Integrated Care Board (ICB) booked in for February. This will be the first time we deliver the training to an organisation. We have lots of work to do still, but we are really excited to do our first training session. We are curious to see how our training will help many ICBs and what that will mean for our work going forward with other organisations.

► Completed a piece of consulting work

We had our first piece of consulting work for the International Disability and Development Consortium (IDDC). We worked as self-advocate experts on a reference group. We looked at the website for the IDDC. We looked at their website and wrote a list of recommendations on how to improve the website for people who have Down's syndrome and learning disabilities.

► DSA website review

We have been reviewing the DSA website and giving advice on two sections of the website. We are looking at improvement and development to make it more accessible. We are editing it to make sure the information is up-to-date and relevant.

► Short information sessions

We have planned some short information sessions on Listen Include Respect. We will be running a webinar series about the Listen Include Respect training. They will take place in the Spring. These will be free to come to and open to anyone that is interested.

► Training on how to be an advocate – Malala



We did some training on being an advocate. It was about our role, and why being an advocate is important. It was really good advice for us on how to be an advocate. And showed us about the impact that this work will make. It also helped with our leadership skills. The training was online and

hosted by Malala Yousafzai. She had some useful tips. It is a good thing for us to keep things moving forward. To see what we can take on being together. She explained it well into sections, we like the way she put it in step by step. It is nice to see how things are progressing.

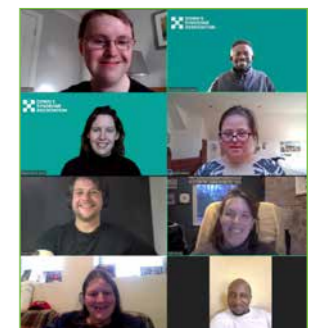
2025 – Our Plans

Catherine

I'm looking forward to keeping on working together to build up new opportunities. I am looking forward to continuing working with my colleagues.

Joe

I am really looking forward to whatever opportunities come our way next. Exploring different ways to address our work with Listen Include Respect, to raise more of the visibility of this work and how it can help Britain.



If you are interested in training on Listen Include Respect, please contact us! training@downs-syndrome.org.uk

DSACTIVE/DSENGAGE Programmes

Update by Kate Harris, Specialist Physiotherapist and Health Promotion Adviser

The DSAActive and DSEngage programmes support children and adults who have Down's syndrome to keep physically and mentally active by delivering fantastic activity sessions.

Every year we assist more organisations to successfully include people who have Down's syndrome via DSAActive. Also, our free, online DSEngage programmes are attended by an increasing number of children and adults, who sometimes let their DSEngage-loving family and friends join in!

DSActive Programme

Did you know that the DSAActive Programme can support the following:

- Sessions for children and adults that have Down's syndrome, including mixed ability, pan disability, learning disability, Down's syndrome specific.
- Leisure and recreational activity programmes. This includes sport, dance, gardening, walking club, Scouts and art and crafts.
- Ongoing, as well as new, activities and sports that already include children/adults who have Down's syndrome or that are hoping to do so.

Are you enjoying an activity or sport session in your area?

We want to hear about it so that we can tell organisations about the support available to them through the DSAActive Programme, which includes:

- Knowledge and understanding of Down's syndrome through DSAActive training opportunities.
- Access to expert knowledge and support available at the DSA.
- Sharing DSA DSAActive programme funding to maximise successful participation and inclusion of children and adults who have Down's syndrome.
- Sharing the benefits of the collaborative work that takes place between the DSA and people who have Down's syndrome, their families, carers and wider community.

We are excited to share recent updates from three of our fantastic DSA DSAActive partners.

Down Syndrome Swimming Great Britain (DSSGB)

British Championships 2024

DSSGB held their third British Down Syndrome Swimming Championships in November. The 2024 competition saw a record 161 swimmers aged 10 and over compete across 44 events ranging from distances of 25m to 1500m.

The two-day competition is the only licensed national event in the UK exclusively for swimmers with both Trisomy 21 and Mosaic Down syndrome. It provides the perfect environment for athletes, from novice through to elite, to excel and inspire others.

Mark Evens, team captain of Down Syndrome Swimming Great Britain, officially opened the Championships alongside Paralympic gold medallist and Championships commentator Liz Johnson. Mark said:

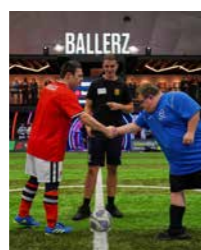
'Once again, it was a fantastic event. Personally, I love being able to race in a competition where it is just my peers who have Down syndrome. Somehow, it brings out the best in me and I can't wait to do it all again next year!'

Here at DSA, we were delighted to continue to support DSSGB as a sponsor. The 2024 Championships were a huge success, with lots of swimmers, their families and friends enjoying the opportunity to take part in such a fantastic, prestigious, welcoming and supportive event.

We look forward to hearing news about the 2025 Championships!



Charlton Upbeats Down's Syndrome Football Festival



Charlton Athletic Community Trust (CACT) and the Charlton Upbeats were proud to host a Down's Syndrome Football Festival at Ballerz, Bluewater, Kent, in October.

The event saw seven-a-side clubs from across the country competing in eight-minute matches, leading to two closely contested semi-finals with the Upbeats being crowned champions following a dramatic final 4-2 victory over Everton.



The festival was hosted thanks to the sponsorship and support of Charlton Athletic Community Trust (CACT), ITRM, the Down's Syndrome Association and Bluewater.

Charlie Macdonald, Director of Youth and Inclusion for CACT, said:

'We're all about giving people with disabilities equal opportunities to enjoy football, enjoy the camaraderie and get a buzz out of it just as any other team does. It's a fun tournament; you get involved in the thrills and spills and see great players who work hard just like any other tournament, and it's been such a great day.'

We would like to say a huge well done to Carl, Terry and all the team at CACT for a fantastic football festival and congratulations to everyone who took part, especially the winners, Upbeats Addicks.

Inclusive United CIC: Turning Lived Experience into Positive Community Impact

Inclusive United CIC are a new DSA DSAActive Partner.

Co-Founder Tracy Light shares with us her inspiring story of how Inclusive United developed out of a clear need for more opportunities in sport and physical activity for people who have learning disabilities.

Founded in September 2023 and inspired by the journey of 20-year-old Thomas Light, a passionate football enthusiast who has Down's syndrome, Inclusive United CIC is a Hertfordshire based not-for-profit community interest company dedicated to creating inclusive sport opportunities.

Recognising Gaps in Opportunities



When Thomas first played football there were very few options for players with learning disabilities.

When he was 10, he joined an inclusive team with our local club St Albans City Youth FC where I also became actively involved.

The transformative effect of football on Thomas's confidence, skills and wellbeing was considerable but as he became older it was clear that local opportunities for young adults with learning disabilities to study, participate or find work experience in sports organisations were limited.

The Spark behind Inclusive United CIC

Thomas completed a Sport BTEC at school but had difficulties finding a Further Education college that would offer a sports course, and we had to enrol on an entry level sports studies course quite a distance from home.

After Thomas completed his studies, securing a sports related, supported internship proved difficult. Many sports related organisations were hesitant to accommodate an intern with learning disabilities, despite Thomas having a designated job coach and support in place.

Instead of accepting these limitations, we realised we needed to turn our frustrations into positivity and with that we launched Inclusive United CIC.



Thomas & Tracy Light

The organisation's mission is to provide inclusive sport opportunities for individuals with learning disabilities, fostering physical fitness, emotional well-being, and social connection.

Inclusive United also offers participants the chance to gain foundation skills to help when looking to explore work experience or roles in the sports industry.

Building Confidence, Community, and Purpose

Thomas has been instrumental in the growth of Inclusive United. With excellent mentorship from Co-Founder Hannah Coote, Thomas has progressed to assistant coach, leading sessions and inspiring participants through his dedication and enthusiasm.

The experience has built Thomas's confidence and led to regular work experience at the sports venue where our futsal (a type of football played indoors on a much smaller court) sessions are held.

Championing Inclusion

Inclusive United runs a variety of activities, including inclusive football, futsal, and well-being sessions, all tailored to the unique needs of young adults with learning disabilities.

These programmes offer more than just physical activity, they provide a supportive environment where participants can form lasting friendships, build self-esteem and experience the joy of being part of something positive.

Through strategic partnerships and community outreach, we provide a welcoming space and prove that inclusion in sports is achievable with the right approach. We plan to expand

and to also support participants interested in pursuing work within sport, helping them develop foundation skills and confidence for the future, ready to be signposted onto services such as DSA WorkFit for potential work placements.

We are delighted to work with and have the support of the Down's Syndrome Association's DSAActive programme. Our vision aligns with the DSA's goal of ensuring there are leisure, recreational, and sporting opportunities for individuals who have Down's syndrome in their communities.

To learn more about Inclusive United, including group bookings or ways to get involved, visit www.inclusiveunited.co.uk

By Tracy Light

Congratulations to Tracy and Hannah and all the team at Inclusive United CIC.

It has been great working with Inclusive United and we look forward to continuing our support of their activities and programmes.



DSENGAGE Programme

Have you tried our free, online DSEngage activity sessions?

They are friendly and lots of fun! Everyone enjoys getting together and getting active with their DSEngage friends.

The DSEngage disco sessions are a favourite for many people. Everyone enjoys seeing their friends and listening to the fabulous song requests, but most people also enjoy having a good dance which is a great way to exercise!

We enjoy regular weekly discos and special themed disco events throughout the year.

DOWN'S SYNDROME ASSOCIATION DOWN'S SYNDROME ASSOCIATION DSEngage DSEngage 				
DSEngage Weekly Timetable You can read about DSEngage and find out how to join DSEngage online sessions at www.downs-syndrome.org.uk/our-work/services-projects/dseengage				
Monday	Tuesday	Wednesday	Thursday	Friday
Weekly Workout 4 pm to 4:45 pm 	4 p.m. Disco 4 pm to 5 pm Evening Disco 7 pm to 8 pm 	Please go to the DSEngage webpage for information about special events 	Wake Up and Dance with DanceSyndrome 9:15 am to 10 am 	Pilates Plus 4 pm to 4:45 pm



We have the pleasure of occasionally working with Suzanne and Tracy from Singing Hands who joined us for our DSEngage Christmas with Singing Hands session, which was wonderful with lots of friends enjoying the signing, singing and partying!

Thank you, Singing Hands, and everyone who joined in and helped to get our Christmas celebrations off to a great start.

DSEngage Christmas Craft was a lovely, relaxed programme where everyone enjoyed the company of craft loving friends.

We made beautiful Christmas wreaths with everyone doing a great job cutting up their chunky strips!

Thank you to everyone who sent in photos of their wreaths being proudly displayed. We hope to have a crafty catch up again very soon.

Visit our DSEngage webpage to look at our weekly timetable of activity sessions and to also see the extra sessions that are available to join www.downs-syndrome.org.uk/our-work/services-projects/dseengage/

AN INCREDIBLE MILESTONE

Bilal has reached an incredible milestone, completing seven years of employment at HCC Solicitors, where he works in the post room.

Supported through the Down's Syndrome Association's WorkFit programme, Bilal plays a key role in stamping and addressing envelopes, scanning mail, and helping keep the kitchen tidy. The company has implemented clear structures and routines to ensure Bilal thrives in his role.

Bilal's Manager, Beth, decorated a meeting room to mark the occasion and arranged a celebration with cake and sweet treats. During the celebration, Bilal expressed how much he enjoys working with the team and chatting with colleagues during breaks.

Beth shared, 'Bilal is a pleasure to have on the team – he brightens everyone's day and is a true asset. We can't wait to see what the next seven years bring!'

Congratulations, Bilal, on this fantastic achievement.



EMPLOYEE SPOTLIGHT

Royal Mail and WorkFit® – James and Joe

James and Joe are WorkFit candidates who are both currently working at a Royal Mail depot in Poole, Dorset.

Late Shift Manager, Steven Grout reached out to the DSA after hearing an interview on Radio 4 about the supported employment programme. Steven felt that there were work opportunities available during the late shift at the depot.

After the dedicated WorkFit Officer worked with Steven to consider suitable tasks, the team there received bespoke WorkFit Employer Training.

James then went to meet the team and immediately made an impression on his work buddy Cameron as they bonded over a love of Pot Noodles!

James

James completed a trial period and now has a permanent paid role. James works one shift a week and his role consists of opening mail bags and making sure the letters are put into the correct areas for 1st class, 2nd class and parcels. James used some visual prompts to help him initially, but he was soon picking up the pace and pointing out any errors.

Steven told us: 'James is incredibly proud to wear his uniform and is very passionate about getting his job done'.

James told us: 'I love it because I get paid. I like to listen to my boss and my supervisor because they help me do my job'.

Joe

Following on from James' success, Steven then reached out to offer another opportunity to a candidate who has Down's syndrome on a different day of the week.

Joe was looking for work and he thought he would like to try the role

and see if it would be a good fit for him. After a couple of shifts, it was clear that Joe had an interest and an aptitude, and he was offered the role on a permanent basis.

Steve told us: 'Joe has settled into his role with ease. Joe is also passionate about his work and is proud to complete his shift, we even get a cheer sometimes when all of his work is done'.

James and Joe complete the same work as other Operational Postal Grade workers and Steven says that 'the work they do is important and valued and I couldn't be happier, having them as part of the team'.

WorkFit buddies play a vital role in fully integrating WorkFit colleagues into the wider team whilst offering a point of contact for any queries or support needs.

Steven acknowledges the commitment Cameron has to his role as a workplace buddy and mentor. He states that Cameron has been instrumental in making James and Joe feel welcome, valued and supported. Not only does he motivate them and celebrate their progress, but he thoroughly enjoys their company as work colleagues.

With the support of the team at Royal Mail, both young men have become successful members of the team. They have taken advantage of the opportunity to demonstrate their skills and abilities and find it fulfilling to go to work and earn a wage.

Joe says: 'It's a happy place and I like the work I do. I am very proud of myself'.

WHAT WE'VE BEEN UP TO...

OCTOBER

Alison Thwaite, our Head of Employment Services, attended the Hilton Abilities Team Member Luncheon in October and was honoured to receive a generous £10K donation to the Down's Syndrome Association on behalf of American Express Global Business Travel.

This event showcased the remarkable skills and talents of people with learning disabilities.

Thank you to Hilton and American Express Global Business Travel, and everyone who helped make this day so special.



NOVEMBER

WorkFit attended an event at Tesco Head Office in Welwyn Garden City, for International Day of People with Disabilities Event. Simon James, one of our WorkFit Officers, filmed a segment for a Tesco film which featured Charlotte, Michael and Charlotte, all of whom work for Tesco, at Head Office or in a store.

We had the pleasure of co-delivering a Lunch and Learn session with Savills. The session was to raise awareness of the WorkFit programme and our work with Savills, placing candidates across their sites in the UK. It was also a celebration, acknowledging the success of Thomas, a WorkFit candidate who is employed as a Visitor Experience Assistant at the Trafford Centre. Huge thanks to Sara Gough, Head of UK Operations for Savills, who has led the development of this partnership.

We attended the BASE Awards 2024, celebrating and recognising excellence in supported employment. A standout moment from the evening was when Severn Trent won the Large Employer Award. They were nominated by DSA WorkFit and the award was presented to Josie, Ian, and Ed, a Severn Trent Ranger, who proudly represented the company on stage. The evening was filled with inspiring stories of inclusion and success.

Special thanks go to all attendees, including H&M who were also nominated by DSA WorkFit and were shortlisted in the Large Employer category.

Congratulations to all the winners and participants!

DECEMBER

To celebrate International Day of People with Disabilities on the 3 December, WorkFit was invited to London Stock Exchange (LSEG) for the Close of Market event which was preceded by a panel discussion on inclusive employment.

We continue, through lunch and learn sessions, to raise awareness of WorkFit, and feed into various consultations and policies at the DSA.



London Marathon 2025

A huge thank you to all the amazing runners who represented the Down's Syndrome Association in the 2024 London Marathon! Together, you raised over £100k which will go a long way in supporting our work. Your efforts made last year's event a great success. We also want to wish the very best of luck to all the runners taking on the 2025 London Marathon next month.

If you have your own place, there's still time to join Team 21 and run in support of the DSA. We'll provide fundraising guidance and a DSA running vest to wear proudly on the day. To learn more or sign up with Team 21, email events@downs-syndrome.org.uk.

Good luck to everyone running this year!



Register Your Interest for the 2026 London Landmarks Half Marathon!

Are you ready to take on one of London's most iconic running events? Participants will have the chance to discover cultural landmarks, historical treasures, and the city's unique hidden gems while running a one-of-a-kind route through the capital. Spaces fill up fast, so don't wait. Sign up today to be the first to hear when registration opens. Whether you're a seasoned runner or looking for your first challenge, the London Landmarks Half Marathon is an event like no other.

To everyone who is running for us next month, good luck!

Mount Kilimanjaro 2025

In January a dedicated team of 17 remarkable individuals completed a ten-day expedition to Mount Kilimanjaro, raising over £150K for the DSA.

This extraordinary group faced high altitudes, unpredictable weather, and physically demanding conditions to not only reach the peak of Africa's highest mountain but also to raise awareness for the vital work the DSA does to support individuals who have Down's syndrome throughout their lives.

The DSA would like to extend a huge thank you to Harrison, Michael, Keegan, Via, Aaron, Martin, Callum, Jon, Johnny, Ryan, Steven, Tommy, Sarah, Ashley, Freddie, Jacob, and Maliha for taking part.

We are enormously grateful to everyone who generously donated and made this trip a success. Asante sana!



Take on an Ultra Challenge for the Down's Syndrome Association in 2025!

Looking for your next adventure? Join Team 21 and take part in one of the incredible Ultra Challenges happening in 2025. No matter the distance, whether it's 100km, 50km, 25km, or a marathon, you can go at your own pace and celebrate your achievement.

With a wide range of events from the Kent Downs to the Lake District, there's a challenge to suit everyone. Explore the full list of events and sign up today by visiting www.downs-syndrome.org.uk/get-involved/walks-and-treks/.

Choose your challenge, join Team 21, and make your miles matter in 2025!

LOTTERY

Join Our Weekly Lottery!

Play for just £1 a week and stand a chance to win up to £25,000 while supporting our vital work for people who have Down's syndrome and their families.

Prizes include:

- £25,000 for a 6-digit match
- £1,000 for a 5-digit match
- £25 for a 4-digit match
- Free entries for a 3-digit match

Your participation makes a real difference – join the lottery today and make an impact while having the chance to win big!

For more details, visit our website: www.downs-syndrome.org.uk/get-involved/lottery/



We're incredibly grateful to Moira Usher, Gilly Hanson Giddins and all their family and friends for their incredible support. Last year, Moira held a concert, which raised over £500. Gilly celebrated her 70th birthday with a 570-mile cycling challenge across Ireland's west coast and raised nearly £4000. Both of these amazing events were to celebrate the transformative impact of our WorkFit® programme.

We are so grateful for your dedication, from inspiring events to remarkable efforts like Moira and Gilly's. Thank you!

FANTASTIC PARTNERSHIP

with The Big Yellow Foundation



Support from foundations and trusts is vital for the work of the Down's Syndrome Association as it enables us to run its many services and programmes. One foundation who have provided incredible support to the DSA since 2018 is The Big Yellow Foundation.



Their steadfast support has resulted in £170,865 being donated to the DSA which has supported our DSActive DSEngage programme, as well as WorkFit®, our award-winning employment programme.

The Big Yellow Foundation works with charity partners to support vulnerable people including people with disabilities. One of the main aims is to offer support to help them to find employment and create a 'better future for themselves'.

The Big Yellow Foundation is the company's charitable cause, which works with seven charities, including the DSA, to help vulnerable adults find sustainable employment.

This is achieved by collecting donations from their generous customers which Big Yellow Group PLC matches. The funds are distributed as unrestricted grants to the Foundation's charity partners.

Gillian Bird, the Down's Syndrome Association's Services Director said:

'The valued support we have received from The Big Yellow Foundation over the last seven years has been outstanding. It has helped us to provide our services and transform the lives of so many people who have Down's syndrome through work opportunities. We would like to thank The Big Yellow Foundation for their continued generosity.'

Meet Sabina Patel-Jhanji, from Partnerships, Big Yellow Group PLC

Please introduce yourself

I work with Big Yellow Group PLC, overseeing partnerships, including charity collaborations through The Big Yellow Foundation, which started in 2018. I am passionate about creating opportunities that have a lasting, positive impact on individuals and communities, ensuring our partnerships reflects our values and drive meaningful change.

Tell us about your role at Big Yellow

My role focuses on building and nurturing charity partnerships through The Big Yellow Foundation. I lead initiatives such as raising awareness of our seven charity partners across 109 UK stores to encourage customer donations. I organise volunteering opportunities for staff, oversee fundraising events and arrange work placements. My aim is to ensure our charitable support aligns with our vision of helping people achieve stability and independence while addressing societal challenges and empowering vulnerable groups to move forward in life.

Tell us more about Big Yellow's relationship with charities

Big Yellow has a long-standing commitment to supporting charities through The Big Yellow Foundation. We focus on partnering with innovative charities that address some of the most challenging issues in society and often support groups that are overlooked. These include charities helping refugees, ex-offenders, people with disabilities and ex-service personnel – vulnerable individuals who need a second chance or a helping hand to rebuild their lives.

To drive this support, we work with our seven charity partners and provide grants funded by donations from both our customers and the business. Additionally, we offer work placements and free or discounted storage to over 200 local charities, allowing them to make a meaningful impact in their communities.

What are your thoughts on Big Yellow's partnership with the Down's Syndrome Association and how does it reflect your ethos of inclusion?

Big Yellow's partnership with the Down's Syndrome Association highlights our commitment to fostering inclusion and empowerment. Through the WorkFit programme, we have created tailored placements that enable individuals who have Down's syndrome to develop practical skills, gain real world work experience and build their independence in a supportive environment with our teams across the UK.

Josh, a participant in the programme, embraced the opportunities to learn and grow, mastering tasks such as handling deliveries, restocking and understanding security.

He says: *'It makes me happy and I feel more independent.'* He also enjoys connecting with colleagues, sharing: *'The people I work with are number one!'*

Feedback from his family has been heartwarming, showing how he has grown personally and professionally.

This partnership reflects our ethos of respect, inclusion and empowerment. We believe diversity enriches both our workplace and the wider community. Supporting individuals with Down's syndrome demonstrates how, with the right support, they can thrive and contribute.

This partnership also raises awareness of inclusive employment and its benefits for individuals' families and society. It aligns with our mission of supporting vulnerable groups through The Big Yellow Foundation. By working with the Down's Syndrome Association, we aim to inspire other businesses to promote diversity and create meaningful opportunities that make a lasting difference.

DANCE TO ME IS A DRIVING FORCE

Dance Syndrome: Learning What's Possible with the Right Support, Together

By Sue, Malcolm, and Jen Blackwell co-founders of DanceSyndrome

Life is complicated. Life as the parent of a child who has Down's syndrome is significantly more complicated.

We believe as parents we are entitled to make personal choices for ourselves and our family following our hearts, acting in the way that we believe is best.

We have been incredibly lucky in many ways. Jen was born with Down's syndrome without additional underlying health needs.

We had no idea what was possible for Jen's life. All we knew was that as a unique individual she had the right to follow her dreams and we, her parents, would support her in any way we could to enable her to live a fulfilling life.

We co-created DanceSyndrome in 2009, when Jen was 28, out of pure frustration. We had spent ten years searching for the right opportunities with the right support to enable Jen to be the community dance leader she had always wanted to be.



Jen had no real friends and felt totally lost and let down by the system, as did we. Having supported Jen through mainstream schooling, at 18 she was no longer part of a daily structure that had helped us all so much to take one step at a time, allowing Jen and our son Anthony to grow and develop into adults with aspirations. We all felt trapped and excluded. Jen told us, *'I have a right to live the life of my choosing, and you do too.'* We agreed but felt lost and confused.

All we knew was that we had to do something. We have always believed in focusing on finding solutions to challenges that present themselves, which often means thinking differently from the check boxes that determine the way of life for families with learning disabilities.

We started DanceSyndrome with nothing. We had no idea what the support should look like, feel like or if it was even possible to create something that allowed people with learning disabilities to experience dance in the community, expressing who they are through a shared language and love of dance. We had no experience of dancing apart from the hours of watching Jen at her precious dance classes each week. All we had was our focus on supporting Jen and a hundred other people who responded to our initial Dancer Search Days to dance together, smile together and 'talk' through dance together.

DanceSyndrome provides dance and leadership opportunities in line with their unique co-delivery model. People with and without disabilities work together to co-produce high quality inclusive dance opportunities and performances, empowering them to become more visible citizens, have their voices heard and succeed in their ambitions.

As DanceSyndrome developed it became much more than dance, nurturing meaningful friendships and life-skills, enabling our members to live with more independence.

For Jen, with the structure and support which DanceSyndrome offered her, she took the step at age 30 to be supported to live independently. This was significant as many different options had not worked for her over the previous 12 years.

Jen and DanceSyndrome are now being recognised through national and international awards and contracts to deliver inspiring and life-changing experiences.



This past 18 months has been the most incredible, extraordinary time for all of us involved in Jen and DanceSyndrome's life.

Jen was honoured in the King's Birthday Honours list, June 2023, with a British Empire Medal (BEM) for her services to disabled people. Jen said,

'I think it shows people with a learning disability what is possible when they have the right support. I hope it inspires others.'

In July 2024 Jen received an Honorary Degree from Salford University for her work with their university students and gave an incredible acceptance speech.

'I'm just bringing happiness, joy and all the good things in life.'

My motto is Dream, Believe, Achieve.

When you have the right support at the right time it can take you further and further and further into the future.

Without my support I wouldn't be who I am.

I am proud of who I am. My disability does not define me or who I am.

My language speaks to me through dance. Dance to me is a driving force.

Me and my family are all in it together.

Thank you so much it means the world to me. This is such an honour for me. And for the rest of my family. And for my dancing family as well.

DanceSyndrome Awards 2024

- Highly Commended in the Northern Power Women Inclusive Innovation Awards
- Music and Culture for Wellbeing Award at the Northern Music Awards presented Nordoff-Robbins
- Gold Organisation (non-profit & government), Stevies International Business Awards
- Silver Organisation (non-profit & government), Stevies Women in Business Awards



When Jen was a child we worked hard on Jen's speech, given that is accepted people who have Down's syndrome find speaking clearly a challenge. However, we believe dancing and becoming her own person, supported by DanceSyndrome, has enabled Jen to develop her speech with a confidence which is remarkable for someone written off at birth. She speaks clearly and passionately, co-leading workshops, giving acceptance speeches, and from conference stages.

In the years since we started DanceSyndrome it has grown into a community that listens, nurtures, encourages, and responds to the individual needs of diverse groups with and without disabilities. People from all walks of life are seeing people with learning disabilities lead, excite, delight and inspire others – on stage, at the front of a room, or in online dance sessions.

We hope to build on the successes of the last two years with ambitious

plans to develop further dance opportunities for children and young people, both online and in communities, across Lancashire.

'With the right support at the right time we can go further and further into the future.' Dr (h.c.) Jen Blackwell BEM

To find out more about DanceSyndrome, in person and online sessions visit: dancesyndrome.co.uk/sessions Please visit Blackwells.biz to learn more about the lived experience Sue, Malcolm, and Jen Blackwell share there.

You can join in the DSA's online Wake up and Dance DSEngage session, run by Dance Syndrome, by signing up at: downs-syndrome.org.uk/our-work/services-projects/dsengage/dsengage-live-dance-class/



JAMES AND THE WACKY WOODPECKERS!

James would like to share with the DSA and his Our Voice friends that he has been on TV!

James's mum, Kate, helps James share his exciting news.

Everyone who knows James was very excited to see him in the latest BBC series of *A Special School*.

James attends Ysgol Y Deri 6th Form.

He attended the same primary and high schools as his brother and sister, but high school had no 6th Form, so he transferred to Ysgol Y Deri where he is lucky to be able to attend 6th Form for 3 years.

Ysgol Y Deri is the largest Special School in the UK and features in the BBC series, *A Special School*. The new series was filmed last school year when James was in Year 13.

James chose Design and Technology (DT) and Business Enterprise as his Y13 option subject and every Friday he worked with his friends Liam and Suzie in the DT workshop.

With the help of his option teacher Mrs Jones and Learning Support Assistant Jack Mortimer, they called themselves *The Wacky Woodworkers* and started a business enterprise making wooden gift crates out of unwanted pallets. Their mission was, 'To save our planet, one pallet at a time!'

The Wacky Woodworkers worked very hard on their woodworking skills and entered a national Young Enterprise (Y.E.) competition which equips young people with the skills, knowledge and confidence they need to succeed in the world of work. Employment skills are an important theme of work at Ysgol Y Deri throughout the year groups.

Lots of schools took part including James's former high school who were really pleased to see him at events. There was no separate competition pathway for specialist provision schools.

At Christmas they made Christmas gift crates and sold them in a Cardiff gift shop, *A Welsh Secret*, on one of the busiest shopping days! At the Easter Trade Fair in the centre of Cardiff's largest shopping centre they won Best Sales Team, and they showed great teamwork, each taking on a



James, Liam and Suzie dressed very smartly and prepared a presentation about their business for a panel of judges. They won Team of the Year and went through to the Welsh finals.

The BBC *A Special School* camera crew heard about *The Wacky Woodworkers* and decided that they'd like to film them which included accompanying them to the Young Enterprise Welsh Finals.

The Wacky Woodworkers had a great day at the finals. They were dressed to impress and presented their business to a lecture theatre packed full of people. They supported each other brilliantly and were the well-deserved and very happy winners of The Team Programme category. Well, they did make over £700 profit!

The Wacky Woodworkers are in episode one of *A Special School*, series three.

We are so proud of James. He's a super young man and everyone gets to see how polite, kind and fair he is. We especially loved to see how he supported all the winners at the Welsh Finals, clapping for everyone, and that made his reaction to *The Wacky Woodworkers* winning Team Programme even more special which we are so glad was caught by the BBC camera!

If someone had told us a few years ago that James would stand up at the front of a packed lecture theatre, let alone speak, we wouldn't have believed it! Despite his speech, language and communication needs James was able to take part and did a great job with the help and support of his fellow Wacky Woodworkers and the YYD staff.

role within the sale, with James as Finance Manager who was a pro with the card reader!

In April they entered the *Young Enterprise South Central Wales Showcase* event.



It is proof of the great things that can be achieved when provided with opportunity, support and self-belief, which Mrs Jones and Jack gave throughout.

The BBC treated the stars of series three to special premier screenings of the new episodes. James, Liam and Suzi got to meet a local celebrity BBC news reader, Lucy Cohen, and joined her on stage for a question-and-answer session with Chris Britten, Headteacher. It was a very special event, and we felt very lucky to see the episode before everyone else.

Episode one was on TV in December and was a huge success with lots of people letting *The Wacky Woodworkers* know what a great idea their crates are, and they have had requests for them from all over the UK and the world! Thanks to James's brilliant woodworking skills we are lucky to have a couple for our gardening and coffee storage.

The Wacky Woodworkers made it into national and local newspapers and their episode was highlighted on Young Enterprise social media saying, 'Their journey filled with laughs, happiness and lots of learning is one you won't want to miss'. Which I felt was perfectly described and, as a parent, everything you want in a school activity.

Final word from James, 'I am excited I am on *Special School* on the TV! *The Wacky Woodworkers* are good. Mrs Jones is great. I like working in the woodwork room with Jack, he is my friend, I like wearing smart clothes out of school and drinking coffee!'

A Special School, episodes one – three are on BBC iPlayer until the end of the year.

Written by Kate Harris

JJ'S TRIP TO PARIS and Disneyland

We interviewed JJ about her recent trip to Paris.

Is this your first trip abroad without your parents?
No, I went to France with Group 3.

(Mum, Debbie): This was a trip with the charity HCPT who take people with disabilities to Lourdes. JJ went with them for a whole week at Easter and she had only met them once before, and some of the supporting volunteers twice!

Tell us what it was like travelling on the train and boat to Paris.

It was good and fun. It didn't seem long or boring.

What was Disneyland like? What was your favourite ride?

Good, lots of rides. I loved Captain Jack Sparrow ride best then puppets, Dumbo and Peter Pan. There was a parade with all the characters.

What was shopping like in Paris?

Shopping was good, not too busy. I used my own payment card to buy things. (Mum says I bought too many magnets!)

What was your favourite part of the trip and why?
Being away with friends.

Is there anything else you would like to share with our readers?

There was a princess carriage on the ferry at breakfast. We saw the Eiffel Tower and went on a boat ride. I took lots of photos on my phone.





TANZIE: H&M AWARDS

By Sharon Smith – Tanzie's Mum

Tanzie's H&M Experience has Been Incredible.

Tanzie is one of the DSA WorkFit® Programme's employees currently working for H&M. H&M employ several young people in their stores. They support them to gain confidence and valuable workplace skills and knowledge. Tanzie started working for H&M in Basingstoke in March 2023, and has become an important and valued member of the team.



Employee of the Month

In February of last year Tanzie won the Employee of the Month award for both her store and for the Southwest region (Area 3). Not only did this provide her with recognition in her local area, but it also gave her the opportunity to engage in a range of events related to The Erling Persson Award.

The Erling Persson Award is given annually to recognise H&M colleagues around the world who, make a difference by putting H&M values into action every day; achieve great results; have the company's best in mind; and contribute to H&M's unique company culture by being true role models who inspire others.

The award was initiated in 2017 in honour of H&M founder Erling Persson who, right from the start in 1947, combined the entrepreneurial spirit and values-driven way of working that still define their culture today.



Tanzie's Presentation

As Area 3's Employee of the Month for February, Tanzie attended a jury day in Cardiff with all the other Area 3 monthly winners. During this day, she delivered a presentation about her love of working for H&M and how she embodies the values of the company.

She also went out for lunch with the Area management team and other area winners and enjoyed an afternoon of ten pin bowling. Her manager Jane Williams told us that Tanzie's presentation was fantastic, and 'she was incredible, and very confident with the group'.

Tanzie had an amazing day at the Erling Persson event.

Tanzie's Celebrations

Although Tanzie did not win the Area 3 vote, she was incredibly excited to be able to go along to the national final jury day and evening celebrations, to support her colleague Greg who was representing Area 3.

This event took place in Milton Keynes, which is where H&M are based. After a night in a hotel, which included dinner with others from Area 3, Tanzie was invited to have a tour of the H&M Distribution Centre.

The event ended with a 'black tie with a twist' event, where the final winner of the Erling Persson Award was announced. Tanzie wore a beautiful H&M sparkly dress with her trademark Dr Marten boots, with flair and confidence.

She had a great time, chatting with everyone including the country manager, who thought Tanzie was wonderful.

This was a brilliant opportunity for Tanzie that was afforded to her through her employment with H&M. She was able to see 'behind the scenes' of her favourite fashion store and meet both area and country managers as part of this experience.

'I love working at H&M so much. I like buying clothes from there and also, I love working on the tills and doing the clear rail, like putting all of the clothes away. I got employee of the month last February. I won a gift card that I have not spent yet. I also won Area 3 employee of the month and got a theatre token, and I went to see Starlight Express. It was incredible. I love my team at H&M. They are hardworking and they help me work more.'

Well done Tanzie!

And thank you to H&M.

Tanzie is one of the DSA WorkFit Programme's members currently working for H&M. H&M employ several WorkFit candidates in their stores.



ABBY'S WEDDING

Hello! My name is Claire. These are photos of my sister Abby and my brother-in-law Stuart's wedding, which was last year. I was a bridesmaid with our other sister, Sian. Abby and Stuart asked me to make a speech and help officiate, which is leading the ceremony. I shared this role with the best man, Seb. Abby and Stuart were legally married two days before, which meant Seb and I could lead the big ceremony for all their family and friends. Being a bridesmaid was the best feeling ever. I really enjoyed being with Sian in all the photos.



I wrote a speech, and that was the easiest bit. I picked up a bit of paper, and as soon as I put the pen on it, I knew what to say. I started with the first time I met Stuart. I asked him lots of questions and decided I really liked him and was ready to give my blessing to their relationship.

When it came to the officiating part, I practiced the lines I needed to say. I led the vows, which is the bit that goes, 'I, Stuart, take you, Abigail, to be my wife', and the exchange of rings, which is the bit that goes, 'Stuart, I give you this ring'.

Finally, I wrote a toast to deliver after the meal. I said me and my family were all proud of Abby and Stuart's stable, loving marriage that they have. Then we raised our glasses of champagne and drank 'to Abby and Stuart'.



It was excellent. I felt really proud of myself that Abby and Stuart had asked me to do these things. I'll be honest, I was a bit nervous, because it was the first wedding I've spoken at. I have done public speaking before, but never at a wedding. But I stopped feeling nervous and started feeling excited that I got to help Abby and Stuart to get married.

My favourite part of the wedding was all of it, but in particular I enjoyed meeting the really nice wedding planner. I enjoyed the ceilidh and the dancing – I danced all the time, for the whole ceilidh and all of the disco. I danced with our friends Gus, Chris, Milly and Chloe. I also loved seeing family members who I don't see very often. My second cousin, Ffion, also has Down's syndrome.

Overall, I really enjoyed this experience, and I hope that other members of Our Voice could be asked to do it, too.



Could you please tell us a bit about yourself.

I am Daniel Barnes, I am 32 years old, I live with my friends in a care home in Kent, I love WWE wrestling and McFly, it's my best, favourite music. I love being with my sisters and love them both.

Tell us how you got your picture on the front cover of the Newsletter 26 years ago? Which is now called the Journal of course!

I went to the creche with my sister while my parents went to an under-5's conference, we had our photo taken while we were playing there.

How do you feel about being on the front cover of the Journal in 2025?

I feel Supercool! I love it, it is amazing.

We understand you work in a charity record shop; can you tell us what that is like?

I love working with my friends in the record shop, we work together to serve customers, price records, and arrange the rota and update our social media page.

What do you love most about your job?

We have great events such as silent disco, a quiz, short break holidays and karaoke and pizza nights. We go out locally to learn about our community, we recently were learning about online safety.

Why is having a job important to you?

I love working with my friends and learning new things and reaching my targets, I like working hard.

Can you tell us a bit more about your drama group Proud Pac? Do you have any shows lined up?

I love drama, it is my favourite hobby! We had a show in November which was great fun, I love to sing my favourite songs, I love musicals, I did a solo of Joseph and the Technicolour Dream Coat 'Close every Door'.

What are your hopes and dreams for 2025?

I hope to take part in some more drama shows and spend time with my best friend Lawrence.

Is there anything else you would like to share with us and our readers?

My sister Kayleigh got married and I am pleased to have a brother-in-law, one day in the future I hope to get married too.



Helpline and Information Centre

0333 1212 300

info@downs-syndrome.org.uk

0333 1212 300

info@downs-syndrome.org.uk

downs-syndrome.org.uk

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

Office hours are Monday to Friday,
10am-4pm. 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

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/



Get active

dsactive.org.uk

Our DSAActive 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

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



langdondownmuseum.org.uk
facebook.com/LangdonDownMuseum

LANGDON DOWN CENTRE

langdondowncentre.org.uk



ds-int.org

Founder

Rex Brinkworth MBE, BA,
Cert Ed, DCP

Patrons

Emma Barton
Olly Bermojo
Paul Bird
Christine Bleakley
Michael Caines MBE
Peter Davison
Dame Judi Dench DBE
Derrick Evans
Perry Fenwick
David Flatman
Shane Geraghty
Sarah Gordy MBE
Sarah Greene
Richard Hibbard
Damon Hill OBE
Georgie Hill
John Humphrys
Kevin Kilbane
Liam Neeson
Craig Phillips
Fiona Phillips
Sally Phillips
Nicky Piper MBE

Officers

Chair	Dr Gerard Coghlan
Vice Chair	Sarah Leggat
Treasurer	Darren Warkcup
Chief Executive	Carol Boys OBE

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

downs-syndrome.org.uk