There is also a feature in this Journal about the publication of the Down Syndrome International Expert Consensus on Cardiovascular Complications of Down’s Syndrome. The DSA was involved with the development of this Consensus and our Trustee, Dr Garry Coghlan, Consultant Cardiologist, explains why the Consensus is such an important step forward for new-born babies, children and adults who have Down’s syndrome.

Abigail Harris, a member of our Information and Training team, has written a piece describing a day in the life of one of our Information Officers. Our helpline is a lifeline for so many people and in 2021 our Information Officers dealt with in excess of 10,000 calls and email enquiries. Find out more on page 13. We are hosting an important online conference about unexplained ‘recession’ in younger adults who have Down’s syndrome on the 28 March. The conference is a partnership between the DSA and the Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG). The DSA is funding this important research and you can find information and how to register, on page 6.

My Perspective is also looking at new beginnings. You will notice that the Journal has had a makeover. We hope you like the new look!

Awareness Week is just around the corner and this year the theme is ‘With Us Not For Us’. It’s brilliant to see how this has been reflected in the ongoing work of Our Voice and in particular their incredible contribution to the Call for Evidence for the Down Syndrome Act which we have included in this issue.

We have asked people who have Down’s syndrome and their families to show us how they are included in their communities, and we look forward to sharing their fabulous stories and photos with you all. We also have a series of excellent webinars lined up which cover a variety of themes, and involve some very interesting personalities, so do look out for those.

I hope all our members have had a positive and happy start to the year. The daffodils are out, and it feels like spring will bring us lots of new beginnings.

Wishing you all a belated Happy New Year.

Kate

Letter from Kate Powell

“Welcome to the March 2023 Journal.”

As always this edition is full of great stories and useful advice.

I was impressed with Our Voice’s motto THIS IS OUR VOICE, HEAR IT ROAR. It certainly sends a powerful message to everybody.

I found the articles on Health and Housing very useful.

I found the story of Millie and her mother truly amazing. Her family and her Brownie pack must be very proud of her. She thoroughly deserves her award. I have a feeling we will hear lots more from this young lady in the future.

I still enjoy doing a regular blog and I look forward to sharing all the stories and useful information from the Journal with you.

Wishing you all a Happy and Peaceful New Year.

Kate
Fancy a holiday in Northern Ireland?

Did you know that the Down’s Syndrome Association owns a chalet at Share Holiday Village in Lisnaskea, County Fermanagh, Northern Ireland?

Lisnaskea is rural and aquatic county with a small population of about 3,000. Towns nearby include Clones, Enniskillen, Belturbet and Ballyconnell and its closest major cities consist of Belfast, Dublin, Glasgow and Liverpool.

The Chalet can sleep up to eight people and can be booked for weekends, midweek Monday – Friday or for one week (seven nights).

The chalet has two bedrooms and two bathrooms. Each bedroom has two sets of bunk beds. This is a wonderful place for all the family but especially the children.

There are great facilities (including a swimming pool, gym, jacuzzi and steam room) and exciting activities which can be booked for your stay. These include canoeing, sailing, banana skiing, archery, and go-carting. Alternatively, you may wish to use your creative skills in workshops for pottery, mosaics, t-shirt printing and many more.

Prices are:

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Fancy a holiday in Northern Ireland?

If you are interested in booking the chalet, please contact the team in Northern Ireland on 02890 776176 or 02890 774723 or email enquiriesni@downs-syndrome.org.uk

Please note bookings can only be made six months in advance.

What’s new this year?

We’ve introduced a child category for our photography section and an exciting videography section which is open to all. We are looking for cutting edge photography and creativity this year, so start thinking about how to break those boundaries!

As we believe it’s time to promote the artistic accomplishments of our community to the wider public, we have joined forces with community partner Libraries Unlimited in Exeter, Teddington Library, and WorkFit partners Hilton and GXO, to showcase finalists work in the form of public exhibitions.

This helps us to gain wider exposure and greater recognition for participants and means a much wider sector of society will see your work.

So, what are you waiting for? Get those entries in!

Competition closes 31 May 2023. Visit our website for more details.

downs-syndrome.org.uk/our-work/our-voice/my-perspective/
HEALTH

AWARENESS WEEK (20 – 26 March 2003) and WORLD DOWN SYNDROME DAY (21 March)

With Us Not For Us

We can’t wait to see all your fantastic #LotsofSocks photos this year on World Down Syndrome Day (WDSD)!

You can either share them with us via our website (downs-syndrome.org.uk/get-involved/photos) or on social media.

Just use the hashtag #LotsofSocks or #WorldDownSyndromeDay to make sure everyone sees them.

If you haven’t yet got a pair of this year’s beautiful design (by Jessica Rotolo from Canada), don’t panic! They’re still available on our website, but you can always wear a pair from another year, or just put on your brightest, most colourful mismatched socks.

Working with people who have Down’s syndrome to create a world where they have the same opportunities as everyone else is the theme of WDSD and Awareness Week. We’ll be sharing fabulous stories, films, online events, resources and more throughout the week so keep an eye on our socials.

Once again, thank you to all our families who generously share their photos with us, please keep them coming!

EXPERT CONSENSUS ON CARDIOVASCULAR COMPLICATIONS in people with Down’s syndrome

Heart disease, especially congenital heart disease, is very common in people who have Down’s syndrome. The quality of care received by people with congenital heart disease and Down’s syndrome is extremely variable in the UK and even more so in less developed countries.

To date there are no guidelines on how heart disease in people who have Down’s syndrome should be identified and managed. This consensus statement is the first step in standardising care by reviewing the available evidence, proposing standards for best practice and identifying critical areas for future research.

Down Syndrome International (DSI), an organisation with representatives from 136 countries, working with the Down’s Syndrome Association (DSA), identified the lack of consistent guidance on the diagnosis and management of heart disease in people who have Down’s syndrome, as a barrier to delivering best care.

With funding secured from Janssen-Cilag Ltd they worked with Prof. Dimopoulos to put together a team of experts from ten countries (ranging from Japan and the USA to El Salvador and Uganda) to develop this consensus document.

Representatives from the DSI and the authors then determined ten areas of interest, foremost being pre-natal diagnosis, management and life-long care for people who have Down’s syndrome and heart disease. Other issues considered included supporting decision making for people with Down’s syndrome, education of professionals and improving care in low and middle-income countries.

The authors then identified, in a structured fashion, over 1600 papers dealing with heart disease and Down’s syndrome published in the last 30 years, of which over 400 were reviewed in detail. From this they put together the most comprehensive evidence statement on heart disease in Down’s syndrome and proposed 41 recommendations for improving care in this population.

In countries that can afford first world care, the heart should be scanned before birth between three and six months into the pregnancy, by someone trained to identify heart defects, if Down’s syndrome is known or suspected.

All people who have Down’s syndrome and heart disease should be referred to and receive ongoing care in expert centres.

Operations on most heart defects in people who have Down’s syndrome are not associated with increased risk but do require specific anaesthetic expertise.

People with congenital heart disease and Down’s syndrome should be observed throughout their lives, by experts in congenital heart disease.

Moving care from paediatrics to adult systems can be traumatic and should be done gradually starting aged twelve years.

Exercise should be encouraged as part of lifestyle management to avoid obesity.

General health management should be managed taking particular care of issues more common in people who have Down’s syndrome (such as thyroid problems, gum disease) and any team aware of the limited ability of many Down’s syndrome people to volunteer symptoms such as worsening breathlessness.

The Down’s Syndrome Association was delighted to play a part in the development of this Expert Consensus.

Dr John G Coghlan
Consultant Cardiologist Royal Free Hospital
Trustee Down’s Syndrome Association

CARDIOVASCULAR COMPLICATIONS

EXPERT CONSENSUS ON

On 7 April 2003.

The DSA and Cambridge Intellectual and Developmental Disabilities Research Group (CIDDGRG) at the University of Cambridge welcomes people with Down’s syndrome, families, advocates, health or social care practitioners, and researchers to the Research into ‘Regression’ in people with Down’s syndrome Online Conference.

Many families over the years have contacted the DSA as their son or daughter with Down’s syndrome has experienced a period of unexplained loss of skills and/or changes in their behaviour. This is often referred to as ‘regression’.

This online, interactive conference aims to:

• Summarise our current understanding of regression and the current research available in this area
• Provide opportunities for interactions with leading researchers in this field
• Provide a space for people with Down’s syndrome and those who care for them to talk about their experiences and hear from others.

There will be three speakers at the event:

Dr Shahid Zaman, Dr Jonathan Santoro, and a third speaker – to be announced

To register please visit: downs-syndrome.org.uk/our-work/services-projects/training/regression-in-people-who-have-downs-syndrome/

To find out more about CIDDGRG please visit: psychiatry.cam.ac.uk/ciddrg/

Highlights:

It is not known how common congenital heart defects are in people who have Down’s syndrome but it is somewhere between one quarter and a half of all those born with Down’s syndrome.

The most common abnormality is an atrioventricular septal defect (AVSD), a hole between both the upper and lower chambers of the right and left heart. Untreated this leads to high pressures in the lung vessels, poor ability to exercise and early death. Other forms of congenital heart disease can also occur, from simple single defects to highly complex multiple defects.

All new borns who have Down’s syndrome should be screened for heart disease. Where possible this should include echocardiography, a sound based imaging of the heart.

Published Circulation 2023

HEALTH

ONLINE conference

Tuesday 28 March 2023 | 12 noon (GMT) – approximately 4pm | FREE

The DSA and Cambridge Intellectual and Developmental Disabilities Research Group (CIDDGRG) at the University of Cambridge welcomes people with Down’s syndrome, families, advocates, health or social care practitioners, and researchers to the Research into ‘Regression’ in people with Down’s syndrome Online Conference.

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Published Circulation 2023
EXPERIENCES OF CONNECTION and well-being
By Stuart Mills and Jane Mitchell

As human beings, our brains are hardwired for connection for our survival. We rely on other people in different ways and on our relationships with others. Our social networks are thought to influence our health and happiness.

This is supported by McGuire and Chicoine in their book entitled Mental Wellness in Adults with Down syndrome who say ‘Generally, no one is able to achieve mental health completely independently. To have a sense of well-being, it usually requires a sense of connection to others.’

The NHS identifies connection and our relationships as the first step to mental well-being for the following reasons:

**They**
- Help us to build a sense of belonging and self-worth
- Give us an opportunity to share positive experiences
- Provide emotional support and allow us to support others

Other benefits are thought to be:
- Better physical health
- More regulated emotions and behaviour

The pandemic had a huge impact on people’s opportunities to connect with others in person.

We have asked people who have Down’s syndrome and their families what connection means to them and the impact of not having it.

**Where**

The information in this article was collated using data gathered in a complex needs parent/carer meeting and in two Our Voice sessions.
We also invited families and people who have Down’s syndrome to complete a questionnaire and received replies from seven parents and three people who have Down’s syndrome.

**Our Voice Groups**

Our Voice is a team of people who have Down’s syndrome who work on projects and tell the DSA what they think about the work we do. We met with the Our Voice 10 years ago, and since that time, we have worked closely with families to develop initiatives that meet the needs of our community. In early 2022, we discuss to what effects their well-being. Throughout the sessions, parents expressed the importance of connecting with friends, family, and peers to their well-being.

We used their feedback to help us provide new resources for the DSA suite of well-being resources (see links at the end of this article).

**Complex Needs Meetings/Questionnaires**

**Who**
We asked how old the person who had Down’s syndrome was. The age range covered was between 12 and 49. Of the questionnaires three people had an additional diagnosis of ASD with one person awaiting outcome of an assessment. One person was deaf and has Developmental Co-ordination Disorder, DCD. Four people were primarily verbal and three primarily used gestures/signs to communicate. One person was living semi-independently in community.

**What did people tell us?**

We asked questions about what connection looked like, how it was maintained and what the challenges are.

Firstly, we asked about the connections/relationships in the person’s life.

For example, the person who responded family relationships were the most important. The relationships varied, from parents and siblings to close relationships with extended family members such as aunts. Some people had a lot of contact with wider family and others maintained relationships through messaging. Also identified were relationships with stepfamilies and adoptive families.

Several people mentioned paid workers (education/day services and support staff) as important relationships for their son or daughter. In some cases, these relationships had continued outside of the paid relationship.

Relationships with friends were also talked about. Some people had many friends, and some had one close friend that they liked to see daily. One person mentioned how their friends were important and that being with friends were the same people. Only one person referred to their daughter having a boyfriend.

We were interested to know how these relationships (outside the family home) were maintained and the level of support that the person needed or did not need.

We heard that relationships were maintained in a wide variety of ways, some remotely and using video calls such as Zoom, Messaging services such as WhatsApp were mentioned, with a few people able to independently message and others needing support.

In some cases, friends and wider family visited the home of the person who had Down’s syndrome and other people talked about visiting friends and family in their homes to socialise.

When it came to meeting up with people, parents would usually make all the arrangements. One parent mentioned how their own or other parents’ commitments would limit opportunities for meet ups to happen.

I feel good when I stay connected with my best friends, I feel good about life.

I feel good when I am out with my friends and family. I feel good because I like to be active, out in the community and enjoying life.

I like to have a cup of tea and I like to talk to people. Singing and dancing and going out with friends for coffee and sometimes get a takeaway coffee. Keeping in touch with my friends and family.

Spend time with my mum, stepdad and other friends and spending time with my sister at work makes me feel good. Seeing friends on Our Voice and seeing my girlfriend as well.

I feel good when I am with my family. It makes me feel good when able to talk to people especially my family about what’s worrying me. Not good – watch news and see really sad things and when can’t see family and friends.

The person who understands me the most is my boyfriend, and I can talk to him about anything. He knows how I feel when I get down or when I get bad and stuff. Helps me feel good – doing something with my friends – speaking to family members face to face and Zoom.

We need to support and provide new resources for the DSA suite of well-being resources (see links at the end of this article).

We then asked what connecting with others looked like. Parents gave us many examples of how people connected. Some people were able to do this independently, others needed supervision and someone to support this. Examples were playing a game or watching a film together, telling a joke to make people laugh, colouring with a friend.

One parent told us that they had come to understand that their child’s idea of connection was different to theirs and that they had come to appreciate the importance of their child exercising choice around connections. They felt that, to some extent, it was important to follow their child’s lead.

Most parents were aware of the positive impact that relationships had for their son/daughter. One parent talked about how their son was visibly happier when around other people. Another talked about how their daughter jumps at any opportunity to go away with school or youth club. A couple of parents talked about how their child needed relationships, but this needed to be balanced with time alone.

They understand me, they like doing the things that I like doing. I don’t have brothers and sisters at home. I like being with people my own age.

A few parents also talked about the negative impact of the lack of contact during the pandemic. For one family the lockdown and isolation took its toll. Trying to maintain connections and contacts was very difficult and resulted in their daughter not speaking for a time and they needed to access help.

Another parent talked about the whole family not socialising even with wider family for 18 months. Their son quickly got used to it and it didn’t seem to bother him, but they wondered how much more progress he might have made, especially socially, if he had spent more time with other people.

Another parent recognised that her daughter really struggled and felt very isolated, and another parent observed how their son became reluctant to go out to either meet people or go to a shop.

What people have Down’s syndrome said about the effects of not connecting:

I feel tense and upset.
I feel frustrated that I can’t see them as much as I want to. I don’t understand why I can’t see them when I want to.
I feel unhappy and sad upset.

Connection: the challenges

There were many challenges identified by parents to maintain their child’s relationships.

Parents stressed that they had to spend time thinking about creating or choosing appropriate environments to facilitate connection for their child. They felt that thought needed to be given, particularly in new situations, to ensure their child had space and time to feel safe, observe and orient themselves before connections were made. It was felt vital to share information about how best to support their child’s connections with significant people in their child’s life so that others could be put in place more widely.

Parents needed time to invest in ensuring social events and activities happened and at times it was hard to find. In some cases, a parent always needed to be present and supervise any meet ups, as well as any online interactions. The need to coordinate with another family in
New study shows a substantially higher rate of fractures in people with intellectual disability

By Stuart Mills

Last year, on 30 September, a large study on fractures was published in eClinicalMedicine, open access journal of The Lancet Discovery Science group (Frighi V et al. Incidence of fractures in people with intellectual disabilities over the life course: a retrospective matched cohort study. eClinicalMedicine. 2022 Sep 30;52:101656. DOI: doi. org/10.1016/j.eclinm.2022.101656).

The results showed a substantially higher rate of fractures in people with intellectual disability, also known as learning disability, compared to people of the same age and gender without an intellectual disability.

Researchers based at the Department of Psychiatry, the Nuffield Dept. of Primary Care Health Sciences and other departments within the University of Oxford, and at Oxford Health NHS Foundation Trust, conducted the most comprehensive study of its kind to investigate the problem. They looked at rates of fracture recorded either in general practice or in hospital records, over a 20-year period, 1998-2017. They compared rates between 43,000 individuals with intellectual disability and 215,000 without, throughout the life course.

The study found that fracture rates are substantially higher in those with intellectual disability.

Fracture incidence starts to rise as people get older, but in those with intellectual disability the rise begins many years earlier than expected.

The types of bones most affected by the fractures point to early onset osteoporosis (thinning of the bones) as the underlying basis for the increased rates. Hip fracture rates are particularly raised. Comparable rates of hip fracture occur approximately 15 to 25 years earlier in people with intellectual disability.

For example, at age 45, women with intellectual disability have a rate of hip fracture similar to 60-year-old women without intellectual disability.

Forty-five-year-old men with intellectual disability have similar rates of hip fracture to 70-year-old men without intellectual disability.

Hip fractures are devastating for the individual, often lead to permanent physical disability, can lead to premature death, and are extremely costly for the NHS and social care. To reduce their impact, they are also preventable if the risk is recognised and adequately managed.

Ongoing research is investigating the reasons for such high rates of fracture in people with intellectual disabilities. These could include impaired bone mass due to accompanying medical conditions and a sedentary lifestyle, and a tendency to fall.

Active fracture prevention strategies should include promotion of safe physical exercise, reduction in the risk of falls, addressing co-existing medical disorders, and ensuring optimal vitamin D and calcium intake. There could also be opportunities to reduce fracture rates through the wider use of existing drug therapies for osteoporosis. Meanwhile, clinical guidelines should be updated to include people with intellectual disabilities in those at risk of osteoporotic fracture, particularly hip fractures.

The study was led by Dr Valeria Frighi, funded by the National Institute for Health and Care Research, and endorsed by the Royal Osteoporosis Society, the Royal Manchester Society and the Down’s Syndrome Association.

We hope to be able to publish the findings of a second study, specifically looking at fractures in people who have Down’s syndrome, in a future edition of the Journal.
POLICY UPDATE

by Chris Rees

With an unprecedented level of upheaval, which saw the UK change monarchs and countless reshuffles of key ministerial roles, I don’t think it’s unreasonable to say the latter part of 2022 was a confusing and unstable time for national policy work. Michelle Donelan’s time as Secretary of State for Education for example, lasted only 36 hours. It was a job just to keep up with all the changes!

As I write in the first few weeks of 2023 it feels at least a little steadier, giving us hope that this year will provide an opportunity for our policy work to move forwards with the aim of supporting meaningful change for people who have Down’s syndrome and their families.

Despite national turmoil we were fortunate that the progress of the Down Syndrome Act earlier in the year meant that the chain of events which will lead up to a final piece of national guidance were already underway.

The first key activity with this was a consultation process, a Call for Evidence, led by the Department of Health and Social Care (DHSC) which will inform the drafting of the national guidance. This Call for Evidence lasted from 19 July – 8 November and provided us with the opportunity to engage with our members in several ways. We initially developed a range of resources (including a blog and an FAQ) which were uploaded to our website, and the promotion of the DHSC Call for Evidence website was undertaken through meetings, newsletters and across social media.

During the consultation period we held 27 online meetings, with some covering themes (Education, Social Care, Employment etc.) and others bringing together specific groups (families of older people, those with complex needs, families from ethnic minorities, our affiliated groups etc).

In addition, an online survey was completed by members and supporters which contained feedback on the key issues in the Call for Evidence, and views on wider issues such as information and advice, the workforce, and the format/ focus of the eventual guidance.

We are extremely grateful to all of those who got involved, shared their views, and told us about their experiences. We learnt a huge amount which helped inform our final response to the consultation.

We expect the next step to be a further discussion on a draft piece of guidance at some point in 2023. No dates yet, but once we hear we will share far and wide.

The other policy priorities for 2023 are likely to be the continuation of both the SEND Review, and the Independent Review of Children’s Social Care. These are both longstanding pieces of work (the SEND Review was initially launched in 2019) and both, having had their own consultation periods in the last year, are expecting to have government responses released ‘early in 2023’.

We know that the decisions and plans linked to both will have a significant impact on children who have Down’s syndrome and their families, and we remain engaged with both processes as the DSA and as a part of two key national networks, the Special Educational Consortium and the Disabled Children’s Partnership.

In addition, we are seeing changes within the health system. The Health and Care Act 2022 brought about structural changes which will see the creation of ‘Integrated Care Systems’ which will come together to plan and deliver joined up health and care services in local areas. Earlier in the year we responded to a consultation looking at the draft structure of Integrated Care Boards (the bodies that will work within the Integrated Care Systems), and work is still ongoing with regard to what is the best way for those new systems to operate, be accountable and deliver change. One significant issue we will continue to investigate is the commitment made by, then Care minister, Gillian Keegan in 2022, linking a specific role in the Integrated Care System to the Down Syndrome Act guidance.

In recent months we have also responded to health focused consultations looking at access to COVID antivirals and access to health advocacy services.

The policy world can feel confusing, ever changing, and hard to pin down but we will endeavor to keep all our members informed of our work, and all relevant national updates through our newsletters, social media and online meetings and webinars.

If there are any policy matters you would like further information on or would like to discuss please contact us on policy@downs-syndrome.org.uk

I have online meetings with my colleagues in the Information and Training Team about twice a week. They might feedback about a Covid-19 meeting they had with the Department of Health and Social Care, or bespoke training sessions they delivered to a school, local council, or healthcare staff, or about the new piece of information on Annual Reviews they have written for the website.

These meetings give us a chance to share knowledge about more unusual or complicated queries. It’s good to have many pairs of eyes looking at what needs to be updated in our literature. At 10 o’clock the phone starts ringing. Usually, we will not know the nature of the call before we pick up. This requires quick thinking and a sound understanding of our subject matter.

A day in the life of the DSA helpline

By Abigail Harris, Information Officer

We are not a counselling service, but we provide a listening ear, information, advice, and practical solutions to difficulties that families are experiencing. We also write letters on behalf of families, most commonly around housing and access to health and social care services.

We can call upon the specialist advice of colleagues and DSA advisers, including Speech and Language Therapy (Gwen Toner), benefits (Helen Wild), adult social care (Chris Watson), behavioural health, and wellbeing (Jane Mitchell) and health queries (Down Syndrome Medical Interest Group).

We will soon be offering a listening service which will offer the opportunity for parents to talk about the things that are troubling them. It will provide a safe space with time to talk uninterrupted and judgment-free.

Just by talking things through people can often make sense of their feelings and are able to find a way forward.

We are not legally trained, but we are able to offer rights-based information and advice.

Some of our calls will last a few minutes whilst others can take an hour and more.

The Helpline provides us with constant input as to the areas we should direct our attention. We learnt about the information and training people have found useful, and where we should focus next.

I particularly enjoy working with Our Voice, two groups of people who have Down’s syndrome we meet with online twice a week. The participants live all over the UK and bring their unique life experiences to assist with the work we do. Our Voice check and edit DSA Easy Read documents, answer questions put to them by external organisations like the NHS and Government departments, and share opinions on our activities such as World Down Syndrome Day. I find the enthusiasm of the groups to contribute the thoughts uplifting, and am grateful to the members of Our Voice for meeting with us every week.

Please remember that if any questions are troubling you, we are a phone call or email away.

As many of our members will know, our Helpline opens at 10am every weekday. Until then, Information Officers will be answering emails and enquiries in our private Facebook groups. Questions there are wide-ranging, from behaviour to social care, ideas for activities to supporting emotional wellbeing. Our Facebook groups include:

- Our Voice – for people who have Down’s syndrome
- Parents and practitioners of people who have Down’s syndrome aged 0-11, 12-18, and 18+
- Parents and family carers of people who have Down’s syndrome and an additional diagnosis
- Family members and practitioners of those who have Down’s syndrome and Dementia

Some of our members will have access to our private Facebook groups. Please remember to keep your posts safe and family-friendly.

My Information Officer colleagues and I take calls about all aspects of life today for people who have Down’s syndrome and their families. These include new diagnoses, either pre- or post-natal; questions about school, college, and work; puberty, adolescence, and relationships; supporting behaviour and learning new skills.

In 2021 we received approximately 10,000 calls and email enquiries.

D.S.A. Helpline is there for families, people who have Down’s syndrome and professionals to call with any questions.

It is a free service open to members and non-members alike.

www.downs-syndrome.org.uk
Inclusion accompanied by accurate...possible within each main section of the document to ensure these were not overlooked.

**Overriding themes**

First, we highlight a number of overriding themes which we found relevant to all aspects of the Call for Evidence, including education:

- Inclusion accompanied by accurate information about Down’s syndrome can raise awareness and help avoid misconceptions.
- People who have Down’s syndrome should have their voices heard in all areas and at all levels of society.
- People who have Down’s syndrome should co-produce all information and co-deliver (as well as co-produce) training packages that follow the development of the guidance.
- People who have Down’s syndrome share a condition, but they are individual people who have a broad range of needs.
- Anyone working in a professional capacity with people who have Down’s syndrome must have access to accurate and up-to-date information about the condition.
- Social advantage plays a part in the life trajectory of people who have Down’s syndrome as it does for everyone in the population. However, it is likely to have a disproportionate effect. Where social advantage does not exist, the effect on the person who has Down’s syndrome is likely to be greater. This may be seen in the arenas of education, health, housing options and social care.
- There should be agreed national and local pathways across health, education and social care to enable services to work together throughout the life of a person who has Down’s syndrome.
- Some of the themes are specific to those who have Down’s syndrome whilst some will have wider relevance to the community of people who have learning disabilities.¹
- The guidance should model and encourage use of person-first language that is not laden with value judgements, e.g. referring to the ‘chance’ of a diagnosis of Down’s syndrome rather than the ‘risk’.

**Education extract**

Next, we share key issues, problems and solutions extracted from the education section of the full submission. We understand and agree with the caveat added to this section in the Call for Evidence given that the mechanisms for long term changes in SEND and Children’s Social Care, the SEND Review and the Independent Review of Children’s Social Care respectively, remain ongoing. Although there are significant issues still facing children who have Down’s syndrome, we will continue to work with partners and networks nationally to see these are addressed and improved.

However, although some of the key issues for children are being addressed through these national reforms, we have included a number of key recommendations for the guidance in terms of general practice and support for children who have Down’s syndrome.

**Early Years are Key**

The vast majority of children who have Down’s syndrome are diagnosed either before or shortly after birth. Health interventions often start from the hospital maternity ward, and the developing needs of each individual child can be assessed and supported. This needs to be the case also as children start to enter nurseries and other early years settings. The guidance should stress that support provided in the Early Years is key and needs to be a priority for local authorities.

¹ Rectifying current challenges to good practice in inclusive education: The benefits to learners who have Down’s syndrome of an inclusive education have been documented over the last 30 years. Historically, development of good practice tended to be regional, with some local authorities targeting capacity building for inclusive education for all learners with additional needs. Inclusive primary education became well established for the majority of learners who have Down’s syndrome during the 2000’s (less so for those learners with more complex needs and dual diagnoses) although more variable (regionally) at secondary stage.

More recently, calls to our helpline indicate that progressive attitudes to inclusive education have stalled and may have reversed. Many families are now being presented with ‘problems’ that with adequate training, attitude and resourcing would be easily solvable. We believe this reflects the lack of training on inclusive practice for trainee teachers as well as resource issues for schools.

The DSA is committed to children and young people having the option to attend local community schools and colleges however complex their needs may be.

Some learners’ needs are met in specialist settings. Teaching and learning recommendations within the guidance should apply to all types of school and college settings.
Parents of learners with complex needs and/or autism provided the following experiences of good practice for their children:

"It was a particularly good experience as my child was in a special needs school. My child had an Individual Education Plan and was integrated into mainstream class for certain lessons. My child had a positive experience in a special needs school, small classes, given attention, made progress. Being able to stay on for 6th form in the same school was helpful. Resource based provision within the mainstrem school was enabled some integration but also the specialist input required.

In practice my son now attends a school locally which means I can talk to school staff in person, get communication, not needing transport. We can work together to write messages in books. It's positive that my son now attends a mainstream school. Good, in the same school was helpful. We have small classes, given attention, made progress.

"Specific learning profile", Adjustments and Support

Each of the points described below is referenced in International Guidelines for Education of Learners with Down Syndrome published by Down Syndrome International 2020.

While every learner who has Down’s syndrome is an individual with a variety of strengths and challenges, there are some common features that are known to affect learning to a greater or lesser extent. These relate to vision, hearing, speech, language and communication, memory and cognition, fine and gross motor skills and health issues. Specific features represent probabilistic attributes and are not necessarily found in all learners who have Down’s syndrome.

Where learning issues exist, provision of learning support and adjustments must be provided. Many of these are not difficult to implement, for example, modification for vision may include materials written in black pen with increased letter size. Reading is a relative strength for learners who have Down’s syndrome, and sign and gesture support the learning of new vocabulary. Learners may experience a range of issues that affect the clarity and fluency of their speech. Keyword sign is an effective approach that supports initial communication during the development of speech and where speech is difficult, learners should be supported to communicate in other ways, such as, for example, sign language, keyword sign, and electronic devices. Support for communication development should continue throughout all stages of an individual’s life. Some individuals with Down’s syndrome have more extensive social communication difficulties and approximately 10-18% meet criteria for dual diagnosis of autism spectrum disorder. Multiagency working must include speech and language therapy input into education. (See Appendix V—Advice on speech and language support).

Visual-spatial working memory is a relative strength, verbal working memory appears to be a significant weakness and long-term memory a relative strength. Adjustments should be made for limitations of verbal working memory and capacity for manipulating information in working memory. The ability to learn by imitation is a powerful strength in an inclusive classroom. There is evidence for specific visual-spatial learning strength. Visual support for learning is an effective strategy for learners who have Down’s syndrome.

The pattern of gross motor development is delayed. Encouraging active movement and participation in physical education, recreation, sports and dance is important and will also promote good health.

Encouraging the use of computers for writing/typing will enhance the ability to communicate.

Occupational therapists can support the development of fine motor skills and advise on devices and aids to compensate for limitations.

Ill-health has an impact on learning, so regular health checks are recommended, as for any child.

Pain is experienced differently by people who have Down’s syndrome, individuals are more sensitive to pain and may have a magnified pain response that lasts longer. Even articulates people who have Down’s syndrome are known to have difficulty expressing the extent of their pain and the location in their body. In an education context, if students exhibit challenging behaviour, it could be they are in pain and unable to communicate.

See detailed age-related recommendations for pre-school, primary, junior and secondary phases within the Down Syndrome International Education Guidelines for Education of Learners with Down Syndrome.

Wider Inclusion at School, College and in Extra Curricular Activities and Youth Services

Service providers should plan for inclusion of children and adults across the curriculum and in extracurricular activities from the outset. This would include participation in school/college clubs, PE lessons and sports, residential trips and other outings, after school activities and youth services. This does not always happen and can result in children and young people missing out on opportunities to develop in ways that will promote their health and wellbeing such as physical activity, friendship and community participation.

Education, Health and Care Plans (EHCPs)

Health and social care service providers should be involved at all stages of the EHCp process. Health has an impact on education therefore the plan should explain health issues, particularly vision and hearing, and be clear that education takes these into account as recommended, for example, for seating position, teaching and learning resources, and equipment such as glasses, magnifiers, hearing aids, soundfield systems. Social care should describe services to meet the child’s needs.

Parents and carers of people who have complex needs and/or autism made the following comments about EHCPs:

"Make EHCPS enforceable" “Updating of EHCPS to reflect changing needs and then ensuring provision is in place” “Getting therapies as identified in EHCPS”

Further and Higher Education

We highlight the need for better access to inclusive higher education, vocational pathways and post 16 opportunities for learners who have Down’s syndrome. Key staff should be helped to see better access to opportunities to support people to prepare for adult life and their chosen occupations.

For example, some learners choose residential colleges with a view to this helping to prepare them for later life. The residential component enables people to experience living away from the family home and to develop independence skills. We strongly recommend that local colleges offer a part time residential option to full this need. Residential colleges may also offer specialist vocational courses that are not available at local colleges.

Relationships and Sex Education

People who have Down’s syndrome (and other learning disabilities) have a right to education, personal development, and to receive accessible information to enable them to enjoy sex.

Relationships and Sex Education (RSE) is essential support for people with learning disabilities to understand their rights, their freedoms to sexual expression, consent, boundaries and safe sex. RSE is also important in providing people with learning disabilities the tools to understand their own body and crucial in protecting individuals from abuse.

It is vital that aspects of RSE begin early in the lives of people who have Down’s syndrome (early years and primary education) and are continued at secondary school and college, and also into adulthood supported by adult social care services.

The DSA has created free, comprehensive resources specifically designed to teach people who have Down’s syndrome about relationships and sex.

Schools and colleges promote employability

For successful outcomes in employment as adults, the journey to work 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 employment among students who have Down’s syndrome and their families.

Schools and colleges therefore must start talking to students about working towards career options early, and certainly no later than 14. They should also be expected to source high quality and well supported work experience placements and taster sessions beyond the traditional sectors of retail, catering and hospitality and supporting with job coaches. Schools and colleges should be liaising with employers so that they can offer support with short-term taster sessions in a variety of locations and settings. Travel training should be included in the EHCPS.

Our Voice selected quotes

Finally, we have selected two quotes from the extensive feedback given by members of Our Voice. All of the feedback given by Our Voice members is included in the full submission.

“Make EHCPS enforceable” “Updating of EHCPS to reflect changing needs and then ensuring provision is in place” “Getting therapies as identified in EHCPS”
Our Voice member responses to the
THIS IS OUR VOICE,

HEALTH
Q: What support do you need to keep healthy?
That includes any health care like:
• Eye care
• Support to move around or communicate
• Mental health support if you feel sad or worried a lot

You might need someone to look after you. Eye care – I wear glasses and I went to the opticians to get an eye test and they put me onto a chair and shone a light into my eyes. I went to the dentist myself and it makes me sad really. I lay down on the chair and it was lowered, and it hurt my back so I have to be careful. I can’t breathe properly when I am on my back.

To keep healthy, I use and follow my DSA Health book. I do this at my GPs every year and have been doing this since the health book started. It covers all things all things about my health. I also attend regular dentist checks, hearing and eye tests. All the people I see to do this are very kind and helpful.

Eat more 5-a-day, people who have Down’s syndrome need to keep me fit and they help me to check my weight. I do nice things it took 9 months to get a support worker to help with that.

I’m normally good at being seen quite quickly. I have practitioners and I get lots of support from Mum, Dad, and brother. I also have my work colleagues. I can change work around for appointments. They let me take a day off for appointments and I was back in the next day.

Finding a competent person who’s fully trained up in their field and in working with people who have learning disabilities, ADHD, Down’s syndrome etc. Who knows that everyone’s different but still has the same needs. It’s really frustrating for me, and I’ve had enough. Less waiting time for support because when I’ve tried to do mental health things it took 5 months to get a support worker to help with that.

Q: Do you have any examples of good health care that you got and why it was good?
Regular appointments at the hospital. It is good as they talk to me first and ask my advice and they can talk to Mum and Dad which I don’t mind as they are my whole support.

Nurse Practitioner is good. My personal trainer at the gym is keeping me fit. My support from one of the Doctors – he said I was good as I sat and didn’t move.

I find it difficult to trust what doctors say to me because in the past I have experienced diagnostic overshadowing. I’ve got negative past experiences. Doctors say they’re doing things for me but I just have to keep my fingers crossed and wait and see.

Getting the right treatment, and the right prescriptions. Getting the right diagnosis. They normally give it to my parents, and they explain it to me. That’s what I want. For my surgery they talk to me and my parents to explain what’s going to happen and what they’re going to do. I have big surgery, so they let me know what they’re doing, and when I go for my GA as well.

Call for Evidence
HEAR US ROAR!

If you would like to join Our Voice, or know someone who might like to get on board, please visit our website*

downs-syndrome.org.uk/become-member-of-our-voice/

I have my two support workers, and my mum to support me with things. I’ve had them for years and they help me with cooking at home, and they’re going to support me to move into my new flat. Shopping, menu planning and cleaning. They may support with other things, which will come up when I move out.

Social support with friends.

Support with everything, cooking, going to shops, looking after money, and learning how to read the time.

Q: Do you know what support there is in your local area to help you live in your own home?

Not entirely sure myself, but I think there could be more improvements with making this clearer online. Because I don’t know so it could be clearer with information on what support is available. Not having the information on support which is available in your local area is a problem.

Yes. There’s the Housing department in our area, our Benefits advisor, and also a financial advisor for support.

I guess support from friends and family with money, I get support when I’m out and about socialising in pubs and clubs. I get support from the DSA.

I understand that support is difficult to get particularly now.

Q: Do you have any good examples of support that you got with Housing? Why was it good?

I am truly grateful for everything my parents have provided me with. They pay the bills, water, drinks, food, the clothes that I wear, the bed that I sleep in. At the end of the day, we should be grateful for what we do have rather than thinking about what we don’t.

At Mencap there are supported living services for people with learning disabilities to learn to be independent such as getting their own place. I haven’t lived with them, but I know they’re a good example.

* To become a member all you will need is to be over 13 years old.
**OUR VOICE**

Staff trying to get us out and about to live independently if we can. Very good at listening to everybody, help me find things. I don’t get stuck under the bed. Organising outings. Helped me to get into my new house and help getting into bed and the shower. Receipts when I buy things. I would like to try the London Marathon.

**TRANSITIONS AND PREPARATION FOR ADULTHOOD**

Q: What could help young people who have Down’s syndrome to get ready for life as an adult?

For example:

- Support to find a job
- Support to go to college
- Learning the job
- Having LSAs

Q: Did you receive information to prepare you for relationships and Sex Education?

Yes, very useful. Remember it sort of but sort of not.

Q: If you imagine a small child – what do you think they need to prepare themselves for adulthood?

Might need a bus pass.

Need an adult. Help them get on buses.

New routes on buses. To be safe on roads. Be careful not to speak to strangers.

Q: Do you have any examples of good social care support you received when you were a child?

For people who have Down's syndrome, they should get in touch with DSA WorkFit. If people are struggling to find jobs, they should go through WorkFit. Support from mainstream school is important. I am not sure if I had support from the social worker. When I was a child but when I grew up to be an adult, I had a few failures with the social workers. I don’t know who my social worker is as it has been changing a lot.

When I was at college, I had staff who helped us to do different things like cooking and cleaning our clothes. They also go to dance and helped us with housework. Quite a lot I would say! It was painful!

I did have good social care support when I was a child. I went to Menap to meet friends with learning disabilities.

I had a befriender who became a good friend who took me to shops to do activities. I went to Hillcrest where you Stay and Play and can stay the night.

I have some examples of good social care support for children. These are my ideas. Speech and language therapy, hearing aids, TAC, social workers, sign language and Makaton.

Q: Do you have any examples of good social care support for children or young people who have Down's syndrome?

My mum said I didn’t get any support when I was a child. I used to have a speech therapist.

I had very good support when I was a baby. I went to Springboard which was special needs playgroup, and Portage where special ladies helped with my speech and how to do things with my fingers. I got to post things through the post box. In mainstream playgroups I had a 1-to-1. All of these people used Makaton with me.

I’m appreciative that I’ve had my family for my support.

Q: What would you like to see in the guidance?

I would like to see new information to do with upholding Human Rights and awareness. Especially for the LGBTQ+ community or diverse backgrounds, not just people who have intellectual disabilities overall. That should be one of the most important topics of conversation.

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**SHERAKS IN VENICE!**

By Scott Wilson, Dad of Ben Wilson, a participant on the trip

The first ever Festival of International Tag Rugby, generously funded by Wooden Spoon and hosted by the Mirano Dragons rugby club in Venice, Italy, welcomed disability tag rugby clubs from across Italy and the UK, including superstars from Sale Sharks.

The Sharks Crusaders Fin Club is a growing Down's syndrome tag rugby team catering for all ages and abilities. They were thrilled to be invited to Venice where our amazing hosts laid out the red carpet. The trip included an evening of inspirational talks, a tour of Venice, and the main event on Saturday 28 October 2022.

Festival day focused on fun and certainly met its objectives. Led out by their amazing Coach Meg, the lads started the day proudly parading onto the pitch during an opening ceremony. The Olympics would have been proud of this! This was followed by a group warm up before a fun packed day of mini tag rugby games.

The festival celebrated what could be achieved through dedicated coaches and structured sessions, with all teams demonstrating some great skills. It showed how sport can break down barriers; across language and culture – but mostly showing that disability shouldn’t be barrier to inclusion. Friendships were formed, teams united, and confidence built as the festival brought everyone together. The day finished with a wonderful party, with fireworks, food and live music.

The event in Venice may have been the first international festival of tag rugby but it’s hopefully not the last. It was an inspirational success showing, without doubt, the benefits of sports inclusion.

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**The Down’s Syndrome Association DSActive Training is a free online training session available for groups and organisations providing recreational, leisure and sporting activities such as Scout groups, sports clubs, drama groups and craft clubs etc.**

By Kate Harrs, Specialist Physiotherapist and Health Promotion Adviser

The training provides an understanding of Down’s syndrome enabling participants to consider and explore how best to overcome barriers which open doors to successful participation.

The goal is to increase the inclusion of children and adults who have Down’s syndrome.

Providers of all types of sessions are welcome, e.g. mixed ability ‘mainstream’, pan disability, Down’s syndrome specific sessions, learning disability etc.

Do you know a club or group providing sessions that include or plan to include children and adults who have Down’s syndrome?

The Down’s Syndrome Association DSActive Programme provides support to clubs and groups to enable the successful participation and inclusion of people who have Down’s syndrome in recreational, leisure and sporting activities.

One means of support is our Down’s Syndrome Association DSActive Training.
I am a good swimmer. I had swimming lessons when I was young. It is fun swimming underwater and playing with my dive sticks.

My first scuba in 2016. Monterey aquarium has a large rock pool. So big to swim in. I put a dry suit on over my clothes. I had a mask and regulator to help my breathing. I floated on the surface and looked down in the water. I was feeling fine it is exciting to be in the water. I found a sand dollar in the rock pool. I am rich!

Trying scuba in the sea in 2017. I tried scuba diving in the sea in Malta with my big brother Owen. It was too cold, and it was a bit scary. I did not like it.

Joining Diveability in 2017. I started going scuba diving with a club called Diveability in 2017. We dive in a swimming pool every month on Saturday. We have lots of scuba friends and after diving we go to the pub for some chips and J2O’s for a drink and talking and laughing. I have learnt lots of skills. I can do buddy checks and empty water out of my mask. I can put the kit together and do the same. I have a hood too. I have a jacket to put over my clothes. I have a hood to put over my mask. I have a mask and snorkel and gloves on too. I have a hood too.

What you have to do is get a rubber chicken and find someone to hook a chicken on their BCD without them noticing and swim away and laughing!

Scuba diving in the Sea in Tenerife in 2020. I have learnt all of my skills in the pool, so I tried go back in the sea again. We went to Tenerife with Duncan my Diveability instructor. On the first and second dive I was scared because of the water was choppy and it was very different to the pool. On my third dive I was brave and, I stayed in the water for 20 minutes.

I was in the water swimming then I saw something in the water. And I pointed at some fish what I have found. They are so colourful and I found some black fish too. I felt so excited and happy that I had done my first open water dive in Tenerife.

Passing my Open Water Certificate in 2022. I went to Wraysbury in June 2022 for my open water certificate. I did four dives with my instructor Duncan. I have to wear a very thick wetsuit and gloves on too. I have a hood too. Because the water is very cold that why I must keep warm. The water it was very dusty and foggy. I saw an old plane in the water and some fish too. And I did some skills like giant stride entry and using a snorkel and regulator recovery.

Now I have HSA open water certificate. That means I can do all of my skills the same as other divers and go in the sea with an extra buddy to keep me safe. I feel good inside me and proud.

Diving in Pemba in 2022. I went diving in the sea on holiday at Pemba in the summer. We were on a boat and sat on the edge of the boat then we had to fall backwards into the water. My buddy was called Sufi. Me and Sufi hold hands together and swim together. And Dad and Owen swam with us, but Mum was seasick in the water! I saw the coral reef it was so so colourful and sea urchins too and lots of fish as well. And I saw an octopus too.

My best bit was in the boat seeing DOLPHINS. Dolphins are my best sea animals in the whole ocean. NOW I WANT TO SWIM WITH THEM!
GWEN MANIKIN

– the first medical manikin for people who have Down’s syndrome

By Gwen

My name is Gwen, and I am the model for the first Downs Syndrome medical manikin. It’s about time that there was one! So, when my mummy saw an ad about one being created, I asked my mummy to volunteer me for the job.

I was really excited to be chosen because I know my mummy and daddy worry about my medical needs and want to know that I am cared for by medics automatically thinking about my needs, like they think of those of a typical child; thinking about my differences, as well as ways in which I am the same as others. In an emergency they want it to come naturally rather than after thinking, owing to time being important for some problems.

I think I may have been chosen because I have the medical needs which are associated with Down’s syndrome and so can help the most people.

To model for the manikin, I was really excited that I had to go to London. Mum and dad told me about the film sets, which they were super excited about, but my brother was most interested in the dummies and manikins and how they were made. I was looking forward to all of it!

I had casts done of my hands and feet – and didn’t persuade me to do that by showing me that it wasn’t as bad as I thought. I had my body scanned. I loved that part. I could see myself on a screen and it really looked like me. I was really interested in the computers and, of course, I wanted to see my brother’s face on screen too! He looked funny and put his tongue out at me.

I got to look around the studios and touch things, but the best thing about the whole experience was the people. They visited me at home afterwards to take some more scans and were really fun and thought about what I like and don’t like a lot. They listened to me and took my choices seriously, letting me be in charge. I tried to eat one of my foot moulds as I had to check how solid it was, so they told me they would get me a chocolate foot after the launch of the Manikin – I am looking forward to that!!

I’ve seen pictures of Gwen Manikin and I thought they were pictures of me in hospital. I can’t get my head around it being a manikin and look forward to meeting Gwen Manikin in person. What I am most excited about is the difference it will make – it is genuinely life-saving and as I said at the start – it’s about time!

We asked Millie about her experience.

What went through your head when you saw your Mum had collapsed and how did you feel? I saw Mommy on the floor, and she didn’t have her eyes open, I shook her, and she didn’t respond so I knew something was wrong. I was worried as she didn’t answer me.

What was the first thing that you did? I did a basic first aid course at Brownies earlier on in the year and we were taught to ring 999 and ask for an ambulance like how they taught us at Brownies.

How did you manage to stay calm? I don’t know I just did; I got the phone and rang 999.

What did you learn in the Brownies that helped you in this situation? I did a basic first aid course at Brownies earlier on in the year and we were taught to ring 999 and ask for an ambulance and let them know what had happened and where we were, and I remembered this and did just that to help Mommy.

We heard from your Mum that this award is really hard to get, so huge congratulations! And how do you feel about getting it? I didn’t know I was getting it so it was a huge surprise, but I was really proud to receive it and show it off to the other Brownies, my Mommy and Daddy cried and said how proud they were of me, and this made me feel all warm and funny.

What advice would you give to others who might have to face a similar situation in their life? Learn basic first aid you never know when you may need it and you could just save someone’s life like I did my Mum.

I really enjoy going to Brownies and learning things with the other children. I get support when needed but generally I manage on my own accord. I try everything the other girls do, and I enjoyed learning first aid and because of it I was able to help Mommy in an emergency and feel so proud that I helped her, and Millie said she was proud of me too.
Hilton won the Best Employer Practice Award for their long-standing commitment to supporting people with learning disabilities to gain paid employment, retain their positions and progress in their careers. Hilton work in partnership with our WorkFit programme, supporting our candidates into a variety of positions within their hotels.

Remco Norden, Senior Director, Regional Operations UK & Ireland, Hilton, said: “Winning Best Employer Practice at the 2022 BASE Awards is a truly meaningful recognition for Hilton. Our partnership with the Down’s Syndrome Association started at Hilton London Metropole five years ago, with the aim to offering young people with learning disabilities fulfilling career opportunities in hospitality. Through the WorkFit programme, we have been able to place 18 individuals across our hotels in a variety of roles – all of which have had an incredible impact for our team culture and guest experience. This recognition fills me with great pride, and I am incredibly grateful to BASE for introducing us to such fantastic Team Members!”

Multipave Ltd also came Highly Commended in this category for the unique employment opportunity that they have given to WorkFit candidate Dan. The team have placed an exceptional emphasis on Dan’s continued professional development and training, in which they intuitively adapt all resources to ensure they are accessible for Dan. They are also strong advocates in sharing the positive benefits of supporting candidates with learning disabilities.

The David Grainger Award for outstanding progress in employment was awarded to WorkFit Candidate Todd Scallon who, with support of WorkFit and his employer Martyn Coles from Coles Scaffolding in Swindon, is working towards becoming a fully qualified Scaffolder, in what could be a UK first for someone who has Down’s syndrome. Todd has a strong work ethic and is a valued and respected member of the team. Todd also won the Significant Achiever of the Year Award at the Employment Related Services Association (ERSA) Awards. Todd proudly said “it feels great” to have won.

Martyn added “I know Todd’s family, and that he’s always wanted the chance to work. We gave it a try, and it’s been five years now – he’s smashing it! Todd’s singlehandedly changing attitudes just by being on the team.”

WorkFit Candidate Callum Trowill, who works as a Teaching Assistant at Maltby Hilltop School in Rotherham, was also Highly Commended for the David Grainger Award. He is incredibly professional and has a talent for communicating with the children in his class. He has shown a constant desire to upskill himself and a dedication to the post that has resulted in him being a valued member of the team.

We would also like to offer our congratulations to the Gym Group who have won the Best Diversity, Equity, and Inclusion Strategy at the Engagement Excellence Awards 2022. Five of our WorkFit Candidates are currently employed by The Gym Group on Inclusive Traineeships which see them studying to gain their Level 1 qualification in Fitness and Physical Activity.

We are proud to see our partner employers and WorkFit Candidates receiving this recognition for their work which really makes a difference to people’s lives. Congratulations to everyone involved – all very well deserved!

We have recently launched some new WorkFit videos that you can find on our YouTube channel. Find out more about the experiences of some of our candidates and employers such as Dan who works as a Depot Facilities Assistant at Multipave Ltd and Shaan who is a Foyer Host at ODEON Cinema. We also have a video which gives more detail on the WorkFit process, explaining the stages that candidates and employers go through when we support them into a work placement. This video features Grace, who was supported into an interesting role at the East Cheshire NHS Trust.

Also check out our ‘News’ section on the WorkFit website where we have some new candidate stories including Joshua who is enjoying his varied role at Big Yellow Self Storage, Harry who works in the VINC1 Facilities team at the Cardiff City Stadium, Scaffolding buildings and Joshua who is loving his role as a Parts Assistant at Marshall Fleet Solutions.

We are happy to announce that our WorkFit programme is still growing. Earlier this year we welcomed 3 new WorkFit Officers to the team who will be supporting candidates and employers across the Midlands, the Northwest and West London, alongside our existing WorkFit Officers who cover the rest of England and Wales.

We held our National WorkFit Conference on Tuesday 7 March which was a wonderful opportunity to hear from some of our candidates and partner employers and celebrate lots of success.

Congratulations to all our WorkFit Candidates who have started new roles recently. We have supported candidates into a range of varied and interesting jobs over the past few months such as Matthew who is an Assistant Groundskeeper at Fulham Football Club, Rory who is a Food and Beverage host at the Cornish Seal Sanctuary, Joseph who has started as an Operations Assistant at Parklands Leisure Centre, and Thomas who is a Customer Services Assistant at Savills Estate Agents.

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

The award-winning WorkFit programme has been given a huge boost thanks to support of the London Stock Exchange Group Foundation. The Foundation made a grant of £21,000 in 2022 to support the delivery of the WorkFit programme in East Midlands and Northeast which has significantly helped to sustain ongoing support to our jobseekers and their employers in 2022-2023. The innovative programme is making a ‘great impact’ to the lives of people who have Down’s syndrome and their families, enabling people from the East Midlands and Northeast to secure employment.

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

For more information visit the WorkFit website: dsworkfit.org.uk
Our Information Officers are available to respond to calls and emails Monday to Friday, 10am-4pm.

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

Our information resources are freely available on our website. People who have Down’s syndrome shape our resources and help to inform our decisions through our inclusive participation activities with DSA Our Voice members. Parents, practitioners and people who have Down’s syndrome can also ask us questions on our closed Facebook groups.

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

Training

training@downs-syndrome.org.uk

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

DSActive

Activities for people with Down’s syndrome

Get active

www.dsafe.org.uk

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

Down’s Syndrome Association

WORKfit

Employment

www.dsworkfit.org.uk

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

The more members we have, the stronger our voice

To find out more about our services, campaigns, consultations, research and how you can become a member visit

www.downs-syndrome.org.uk