

journal

146 Spring/Summer 2023



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Disclaimer

The Journal is designed to provide a communication forum for members of the DSA through which to facilitate the exchange of information on topics related to living with Down's syndrome. Unless indicated otherwise, the views expressed in The Journal are those of the authors and do not necessarily reflect the official positions or policies of the Down's Syndrome Association.

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Contributing to the Journal

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

We welcome contributions from our members. If you would like to contribute to a future issue please find details on our website: www.downs-syndrome.org.uk/our-work/information-services/dsa-journal/

LETTER

from the Chief Executive



Carol Boys

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.

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.

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 Gerry 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 'regression' 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 a little different this year. As well as introducing exciting new photo/age categories and a short film category, we will be displaying the shortlisted images at public exhibitions across the country. There is still plenty of time to enter. The competition closes on 31 May, and we cannot wait to see your entries!

Carol Boys,
Chief Executive

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WELCOME

Letter from Kate Powell

"Welcome to the March 2023 Journal."

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

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 for the DSA, and attend monthly meetings on Zoom with the Down Syndrome International (DSI) ambassadors from around the world and discuss our problems and hopes.

Wishing you all a belated Happy and Peaceful New Year.

Kate



ON THE COVER:

My Friend Sibel
Photo by Hugh Graham.

Hugh's photo of Sibel was shortlisted for the My Perspective 2022 Competition.

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Judge's Choice Award Winner 2022

Jonathan Grosvenor



NEWS

NEWS

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:

Weekend:	Friday – Sunday	£150.00
Mid-Week:	Monday – Friday	£250.00
Full Week:	Friday – Friday	£350.00



MY PERSPECTIVE 2022

It was so good to be back at Normansfield last November for our My Perspective 2022 event!



Stephen Thomas Award 2022
Carlos Biggemann



People's Choice Award Winner 2022
Lucia Sedano

My Perspective not only brings our community together, but it also highlights the incredible skill and talent of our competitors who help to spread wider societal awareness about Down's syndrome.

Congratulations to our winners, to everyone who got involved and a huge thank you to our sponsors, our judges and guest of honour Sally Phillips.

MY PERSPECTIVE 2023

IS OFFICIALLY LAUNCHED WITH ITS OWN BRAND-NEW LOGO!



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/

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.

AWARENESS WEEK

(20 – 26 March 2023) 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 mis-matched 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.

UPDATED NEW FRIENDS AND FAMILY LEAFLET



Like our *Congratulations on the Birth of Your Baby* leaflet, our new *Friends and Family* leaflet also forms part of our new parent pack, and is available on our website.

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

EXPERT CONSENSUS ON CARDIOVASCULAR COMPLICATIONS

in people with Down's syndrome

Published Circulation 2023

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 merited review 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.

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.

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 by a 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*



ONLINE conference

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

The DSA and Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG) 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 CIDDRG please visit: psychiatry.cam.ac.uk/cidrrg/

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 has.

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 groups online, early in 2022, to discuss what effects their well-being. Throughout the sessions, people cited the importance of connecting with friends, family, and peers to their well-being.



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

I feel good when I am out with my friends and family and my peers. 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 I sometimes get a takeaway coffee.

Keeping in touch with my friends and family.

Spend time with my mam, stepdad and my 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 daily covid figures 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 low and stuff.

Helps me feel good – doing something with my friends – speaking to family members face to face and Zoom.

We used their feedback to help us produce new resources for the DSA's 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 everyone 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 and their parent's friends were the same people. Only one parent referred to their daughter having a boyfriend.



He enjoys sharing an interest, having someone watch movies with him, interacting over a meal or drink. Connections of all sorts, even quiet ones are very important. However, there are many times when something has been interrupted or not occurred and he has great difficulty understanding why (when it occurs on a regular basis). He withdraws easily into himself if the tone of someone is raised or snappy and shuts himself off with his headphones. He especially loves going to the theatre to see musicals or to the opera with his family or friends.

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

We heard that relationships were maintained in a whole 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 need my mum and dad to help me make arrangements and transport me. I see my friends at youth club once a week. I see my friends at school but I have just left and will be going to college so I am worried I might not see them. I do use social media, WhatsApp and FaceTime which helps.

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.

Some parents raised an interesting point about their child's peers. They felt that their child's perception of who is a 'peer' might be different to their own. A parent mentioned the example of her son preferring the company of, and seemingly identifying with, older people.

For some people connection was observing others in a group and spending time with people without obvious interaction.

I am shy so only have 2 real friends and a boyfriend who I see outside of school. I have to rely on my mum and dad. It's difficult because I'm not independent enough to use public transport on my own and my friends and I have to go to each other's houses or a supervised activity to stay safe. Some of my friends in school are non-verbal or can't use social media. Also, as I was at a special school most students used school transport, so it was difficult for my parents to meet other parents to get to know them.

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 lockdowns 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 who 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 and upset.

Connection: the challenges

There were many challenges identified by parents to maintaining 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 the same supports 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 this. 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

a similar situation could mean that these meet ups and interactions would not happen as often as hoped.

Some parents talked about the challenge of the person themselves not wanting to go out or do anything. For some people this had increased in recent times.

One parent talked about financial restrictions and geographical isolation adding further challenges.

In some situations, parents felt that one-to-one supporters in school or the community may actually be a barrier to connection for their children.

Conclusion

We may assume that being connected with people is about having lots of friends and family that we interact with regularly. However, connection will mean different things to different people. Something that has come out of our discussions is that for some people connection can involve a sense of belonging to a group, such as a class at school. It may be about spending time with people who understand without obvious interaction. The information we gathered highlighted how many people are totally reliant on others to initiate and facilitate connection and relationships.

My friends are really important to me. They make me happy. I have a very small family. I love my sister but she is married with four young children so I don't get to see her much.

Helpful resources

Well-being – What does it look like and what to look out for (downs-syndrome.org.uk/WellbeingWhatToLookFor/)

What is well-being? (Easy read) (downs-syndrome.org.uk/WhatIsWellbeingEasyRead/)

Sources

1. McGuire and Chicoine, *Mental Wellness in Adults with Down syndrome*
2. tanveernaseer.com/building-relationships-key-to-leadership-success/



A COMPLEX NEEDS Case Study

by Tatty and George Bowman

Parent name: Tatty Bowman

Person who has Down's syndrome and their age: George Bowman, aged 18

What is something you admire about the person with Down's syndrome?

George always surprises us. If he can't do something he finds his very own way of achieving what he wants. He is resilient, loving, and humorous.

Could you share with us a bit about the person with an additional diagnosis/complex needs, their level of support, developmental history and significant events?

George was diagnosed with Down's syndrome at birth and ASD at 3.5 years old. He is nonverbal and still in pads. He needs support with everything and constant supervision. He is now 18 and on the cusp of moving from school to college.

George understands more than people presume and listens to far more than anyone expects! He loves people and will show love or fondness for his familiar adults through hugs and touch and beautiful high pitched joyful sounds.

He does find some things difficult like transitioning from one activity to another. But his emotional regulation is improving as he matures.

He doesn't yet have a form of communication which has worked for him but he consistently finds a way to let us know what he wants and what he feels.

Although life is often stressful, it is also deeply meaningful. You don't need words to say 'I love you'

Could you share any help/support provided by the DSA that has been helpful, for example the complex needs Facebook group, web resources, parent meetings, telephone calls or training?

The DSA offered many training sessions which I attended when George was little. When he first received his dual diagnosis. Stuart Mills gave me articles to read so I could begin to understand our new trajectory.

Also, the online monthly DS/Complex needs group is invaluable and allows me feel part of a community which understands me and which I can in return offer support to. Finding where you belong is very important when you realise your child/young person doesn't resemble a person with Down's syndrome alone.

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 a large extent, 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-existent 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 fracture.

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 Mencap 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

POLICY UPDATE

by Chris Rees

With an unprecedented level of upheaval, which saw the UK change monarchs, take on three prime ministers 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 all of 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 mailouts, 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 these 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 changeable, 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.

DSA's 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.

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.



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), behaviour, 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 hear 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 their 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

**DSA
HELPLINE**
10am-4pm
0333 1212 300

ONLINE BABY and support group



By Christine Thorburn

"We really appreciated the DSA's Pregnancy and Baby group. We attended following the birth of our little one & after feeling bombarded by very medical information during our pregnancy, it was great to be in this group. It was supportive, celebrated our babies, provided an outline of how the DSA is there for us and gave really useful, uncomplicated advice and strategies from very knowledgeable and approachable specialists. Thank you"

Our online Baby and Pregnancy Support Group runs every second Wednesday between 1.30pm-2.30pm.

These sessions are free and offer support for parents of babies up to 18 months of age and expectant parents looking forward to welcoming their new baby.

To register, please visit us here:

downs-syndrome.org.uk/our-work/services-projects/training/baby-and-pregnancy-support/

Online
Baby and
Pregnancy
Support Group

Down Syndrome Act 2022 Call for Evidence: Education Extract

Thank you to everyone who contributed to the DSA's Down Syndrome Act 2022 Call for Evidence submission. We especially thank members of Our Voice who considered every aspect of the call for evidence and gave us their views.

In this Journal edition, we share an extract on the topic of education.

Whilst we included extensive feedback quotes in the appendices of the full submission, we chose to include feedback from parent carers of people who have Down's syndrome with very complex needs and/or autism 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 preconceptions.
- 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

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.

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 feedback on their experiences of good practice for their children:

Y3-6 was a particularly good experience as my child was in a special needs cluster unit.

My child has 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 a mainstream school good, enabled some integration but also the specialist input required.

It's positive that my son now attends a school locally which means I can talk to school staff in person, great communication, not needing transport. We can work together with school and aren't needing to write messages in books.

Good practice recommendations

Good practice recommendations include school/college leadership allocating time for teachers to plan, a shared vision of inclusion, working in partnership with families, teachers who understand that they are responsible for learning of all students in class and teachers who guide the work of teaching assistants. A high level of additional learning support assistance to meet individual needs is common.

Teacher training and further professional development should be available to teachers. Guidance should reinforce that learners who have Down's syndrome can be taught the curriculum for the year group, adjusted to enable engagement with learning outcomes. All teachers should understand and know how to support behaviour (for all students with a learning disability). All schools/colleges should know about and be able to implement recommendations to promote learning for the varied needs of children and young people who have Down's syndrome as the strategies and modifications should be within their 'skills toolkit' for teaching any learner with similar additional needs/s.

'Specific learning profile', Adjustments and Support

Each of the points described below is referenced in International Guidelines for Education of Learners with Down Syndrome² 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/recording 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 articulate people who have Down's syndrome are known to have difficulty expressing the extent of their pain and locating it on their body. In an education context, if students exhibit challenging behaviour, it could be that they are in pain and unable to communicate.

See detailed age-related recommendations for pre-school, school, college and continuing education within the Down Syndrome International Education Guidelines for Education of Learners with Down Syndrome.

Wider Inclusion at School, College, 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 day 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 EHCP to reflect changing needs and then ensuring provision is in place'

'Getting therapies as identified in EHCP'

Further and Higher education

We highlight the need for better access to inclusive college courses, vocational pathways and post 16 opportunities for learners who have Down's syndrome. We would also like to see better access to opportunities to support people to prepare for adult life and their chosen vocations.

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 fulfil 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 exist as sexual beings, and to receive accessible information to enable them to enjoy sex.

Relationships and Sex Education (RSE) is essential in supporting 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 employment

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 EHCP.

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.

'For my support I watched videos to watch someone else do it. It helped me to concentrate and learn. Sometimes I had help with money, and LSAs helped me with my subjects. I worked with friends in a group. Teachers helped me when I was stuck with my work. At secondary I had LSAs, and now I'm in college I had help as well. If you get stuck with your work, you can put your hand up and the TA or teacher will come round and help you.'

'I went to special school. Do you know what? I remember everything about school and it was my number one favourite. I got support for going on school trips. We had a teaching assistant, 1, 2 or 3. They were there some of the time, to help you if you got stuck. They helped us with writing, spelling and making sure you wrote on the lines. They helped me in case I got bullied. I had very good friends at school.'



Our Voice member responses to the THIS IS OUR VOICE,

Call for Evidence HEAR US ROAR!



The Our Voice group is a vital, highly valued part of the DSA's work. Our Voice members are deeply committed to creating positive change for people with Down's syndrome, and as an organisation the Down's Syndrome Association is hugely grateful for their valuable insight, humour, and honesty.

They played an important part in the development of our response to the Down Syndrome Act Call for Evidence. Below we've shared a snippet of their views under the headers of Health, Housing and Transitions and Preparation for Adulthood. Our Voice members worked hard on their responses, spending eight sessions putting them together. The completed Call for Evidence document is available from DSA upon request.

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. Eyecare – 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 should take health books to the doctors. Help you to keep your feet healthy, I see a foot therapist and support takes me to do this. A support worker helps me make health appointments. Making healthy choices on the shopping list that you will need help with. Talking to someone if I am feeling sad. My support helps me to go out to the gym to keep me fit and they help me to check my weight. I do nice and relaxing things for myself to make me happy. I enjoy having exercise in the park to walk our dog.

Q: What would help you to get the right support with your health?

This is anything that you think would make your health support better.

Like better information, training for health staff or waiting less time for support.

I can move around and communicate so I am quite lucky. I have weekly checks and have my health book. I have a nurse practitioner 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 9 months to get a support worker to help with that.

I'm normally good at being seen quite quickly. I have a very good GP and good support. I've got the best support workers.

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 diagnoses. 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.

*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/



HOUSING

Q: Do you live on your own in your own home? Do you plan to live on your own in the future?

I have been living on my own for about 20 years. At first it was all right because I was living with my brother to start with, and we were renting the house off my mum. I got frustrated and wanted a place on my own where no one would interfere. After that I moved into my own place and have been trying to do it on my own but with some difficulty. I have always lived in the same area. I would eventually like to move out of the area.

Currently I live with my parents, I am truly grateful for what I have with my parents. At some point in our lives, we might come across a special someone, and that would be the time in my life when I might start living not by myself but independently with a partner

Yes! I plan to live on my own in the future with the Disney Channel.

I live with my parents, but I would like to live on my own in the future. I would like to live with friends but close to my family. I look forward to leaving home but I will need help to support me.

I live with my boyfriend. In the future I want to go on the ground floor due to problems with my hips.

Q: What support would you need to live by yourself in your own home?

I have been shouting for support for about 10 years now and they are still getting it wrong. I have recently come out of paying privately and even they got it wrong and said, "because I'm so capable, I'm a unique case, and they cannot support me." They don't understand and it's frustrating. Recently I found out that I had ADHD and with this comes unfinished projects, so I've got so many things round here that I need to do but there's a 'wall' which prevents me from doing it. It's about understanding my needs. I need support to communicate my needs.

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 am 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.

Staff trying to get us out and about to live independently if we can do. Very good at listening to everybody, help moving things if things 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 and help with budgeting and benefits. Christmas presents for family and activities. Help with getting ground floor flat which will be after operation as I will need it after I have recovered.

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

I went to different schools before I went to college. I go to college now. I remember looking around the building and seeing what courses I wanted to do. The first time was a bit difficult, but I got used to it. I was in different classes for each term. I currently do drama on Mondays. The classes I do is different from week to week and every day. I go on bus there and back on my own. Someone helped me to learn the route. The 1st time someone taught me, the 2nd time my family took me and then the 3rd time I was on my own.

I had support when I was in school. I had support with my maths because I struggled with money. If someone needed support, I would take them to the local job centre. Having a job is a good thing. I just love it. helping young people to think about working is helpful.

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. I am in my last year of college at my special school, and I don't which college will suit me best. I am going to a youth club. I would like a P.A. to take me to swimming, dancing, and social activities.

These are my examples to help people with Down's syndrome prepare to be an adult:

- Talking to careers teachers
- Work experience
- Travel training to get to the job
- Learning the job
- Support to fill in the forms
- Having LSAs
- Help to learn to use money

Q: How do we prepare for adult life?

Can have a flat or a house.

Q: Transition from school to adult life. Can you remember what you did?

Hard question – I don't know. On living independently, I did a couple of days with parents and looked at new house. Stayed a few more days with parents and then moved in.

Q: What could help people with Down's syndrome to prepare?

Write a list. Make sure you have clothes packed, toiletries. Learn to do food shopping; learn how to pay bills.

I work at three different jobs. I help others, make them tea and coffee. Washing and drying up and dishwasher. Sou Chef. Make supper I only do it with my sister and brother but not Mum and Dad. Doing a birthday sleepover, going to do first one in ages. At second job help making teas and coffees. Look after people – interacting. Chatting and seeing how people are. At charity shop job I do every single job and I like it. Sort out CD's and DVD's and labelling. Sometimes work on till.

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 workers 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 washing our clothes. They also to us 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 Mencap 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, TAs, 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 playgroup 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 those 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.

SHARKS IN VENICE! DSActive

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

Activities for people with Down's syndrome

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 focussed 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 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.

A rugby community was formed and has ignited a spark that will surely be a catalyst for future events.

Reluctantly, a thoroughly exhausted Sharks team flew back to Manchester, taking back memories that will last a lifetime but also having grown in a few short days as a family, a team, and as individuals.



With thanks to Megan Kirby, Disability and Inclusion Officer, Sale Sharks, for submitting the article to DSA.

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 Harris, 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 opens 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.

GET INVOLVED!



*"My name is Harvey.
I am 17 years old.
I have Down Syndrome.
I love to swim."*

HARVEY'S SCUBA DIVING STORY

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 J20'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 take it apart afterwards. I can do under water skills like regulator recovery. And remove and replace my kit underwater.

I enjoy playing a game called hook a chicken on someone's BCD (buoyancy control device). It is a funny game.

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 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!

STATESIDE Adventures

Hi, my name is Bethan.

In March 2020, I was supposed to represent the DSA at the World Down Syndrome Day Conference at the United Nations building in New York.

I was very excited to go, but unfortunately it was cancelled due to Covid.

I was very disappointed, so my family agreed we would go to New York when we could. Our trip happened in June 2022, and we went to Toronto and New York.

We did lots of things, like seeing the Statue of Liberty, the Empire State Building and going on a Harbour Lights cruise.

My favourites were the Friends Experience, the Guggenheim Museum where Mr Popper's penguins slid down, and the theatre. We went to see Harry Potter and the Cursed Child, and also went to the ballet.

We went to the UN building for a guided tour, which I really enjoyed. As part of the tour we went in the conference room where I would have given my speech. I had some photos taken in the conference room.



"I had the time of my life in New York. It was fab!"



Work experience for Izzy

By Abigail Hooper-Brown

Izzy is 15 and has been home schooled for most of her secondary school years due to ill health and a lack of suitable placements.

Izzy started at Pencalenick School in Cornwall in September last year.

The staff have been amazed at how capable she is and put her straight into a work experience placement at a local cafe.

She's done so well there that she has become the first student to be offered an extended placement, doing 1 day per week for the foreseeable future working the till, baking cakes, dealing with stock etc. Izzy absolutely loves the cafe environment and it's wonderful to see her confidently interacting with her customers.

The school have also now bought an expensive coffee machine so that she can progress in her barista training and encourage other students who have

varying disabilities to reach out and do the same. Izzy said

"I felt really happy because everyone was really nice and I enjoyed being on the till and making food like sandwiches and cakes. When I found out I could go back every week I felt even more happy because I love it!"

This opportunity has definitely given Izzy more confidence and the enjoyment she gets from working with people in a professional way, especially chatting with the customers, makes her feel very grown up.

She has surprised everyone with how capable she is and is looking forward to working in this type of setting after college. We are extremely proud of her.





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.



The real Gwen!

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 – big brother had to persuade me to do that by showing me that it wasn't scary to put my hands and feet into a bag of gunk!!!! I made him do it first and he seemed to be

okay, so I tried it and 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 lifesaving and as I said at the start – it's about time!



SUPERSTAR IN ACTION!

By Heather and Millie Pearce

Millie is ten years old and lives in Wolverhampton in the UK. Last year Millie saved her mother's life. This is her incredible story.

Millie's mother is called Heather and she has a heart condition called Paroxysmal Atrial Fibrillation Tachycardia, which can cause an irregular and often fast heartbeat.

On the morning of 3 November 2022, whilst Heather was getting Millie ready for school, she became lightheaded and her heart starting racing.

Heather sat down and did some breathing exercises, but nothing helped her heart regulate. She crawled into the living room and blacked out.

When Heather came round Millie was by her side, holding her hand and telling her that she would be OK. Millie was talking to someone on the phone and Heather realised she was speaking with the Ambulance service.

Heather said:

"I'm super proud of Millie, of what she did that day. Who knows what the outcome would have been if she hadn't thought quickly and got an ambulance. My heart went into Supraventricular Tachycardia, meaning that my heart was beating 235 beats a minute instead of around 80. My heart was emptying of blood more quickly than it was filling up. That's what caused me to pass out. Without help I could have gone into cardiac arrest and the outcome could have been so different."

Millie, who is a Brownie, earned a Mercia Star Award, which is given to exceptional young members of the Girlguiding community. The Award can be given for one or more of the following, demonstrating great resilience, acting as an exceptional role model, and showing initiative in response to an emergency situation.



Heather with her proud Mum and Dad

Heather describes her daughter as laid back, funny, thoughtful, determined, loving and fearless going on to say:

"We have always instilled in Millie what to do if she found us on the floor, unresponsive and regardless of her disability it proves she is capable of dealing with an emergency."

She is so deserving of the Mercia Star award. We have always supported Millie in social activities and attending Rainbows then Brownies has helped her learn so much and she starts Guides very soon now that she is 10. Her Down's syndrome does not define her it makes her who she is today and with our love and support she can achieve whatever she wants, and I wouldn't change her for the world."

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?

Mommy has always said if I ever find her or Daddy on the floor, I should 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 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 Mommy.

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 Mommy 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 of 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 Scanlon 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'd 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 VINCI Facilities team at the Cardiff Welsh Government buildings and Joshua who is loving his role as a Parts Assistant at Marshall Fleet Solutions.

We are happy to announce that our WorkFit team is 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.

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

For more information visit the WorkFit website:

dsworkfit.org.uk



LSEG FOUNDATION supports DSA

Partnerships with companies is vital for the Down's Syndrome Association (DSA) as it helps to enable the running of programmes and the overall work of the charity in supporting people who have Down's syndrome, their families and carers.



Alison Thwaite, WorkFit Manager said, "We are really delighted with the amazing grant from the LSEG Foundation for WorkFit East Midlands and Northeast. The grant will enable more people who have Down's syndrome to secure sustainable work opportunities, so transforming their lives. Our sincere thanks to the LSEG Foundation for this very generous grant to the DSA to allow us to continue our valuable work."

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 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.

"Supporting organisations such as Down's Syndrome Association plays a vital role in delivering the LSEG Foundation's mission of facilitating economic empowerment through education, employment and enterprise. These partnerships deliver impactful, localised programmes such as WorkFit, to remove barriers to opportunity and enrich our communities," commented Luke Manning, Head of LSEG Foundation.



WORKFIT Update

We are delighted to share the success of some of our employer partners and WorkFit Candidates at the British Association for Supported Employment (BASE) Awards. These awards recognise and celebrate outstanding practice in the field of supported employment in the UK.

Can you #Challenge21?

We are aiming to raise £21,000 as a community, why not get involved?



For ideas, inspiration, and registration visit www.downs-syndrome.org.uk/get-involved/challenge-21/

Helpline and Information Centre

0333 1212 300

info@downs-syndrome.org.uk

0333 1212 300

info@downs-syndrome.org.uk

www.downs-syndrome.org.uk

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

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

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

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

Our information resources are freely available on our website.

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

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

Training

training@downs-syndrome.org.uk

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.dsactive.org.uk

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



Employment

www.dsworkfit.org.uk

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

Founder

Rex Brinkworth MBE, BA,
Cert Ed, DCP

Patrons

Emma Barton
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
Nicky Piper MBE

Officers

Chair	Georgie Hill
Vice Chair	Sarah Leggat
Treasurer	Darren Warkcup
Chief Executive	Carol Boys

The more members we have, the stronger our voice

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

www.downs-syndrome.org.uk



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

**LANGDON DOWN
CENTRE**

www.langdondowncentre.org.uk



www.ds-int.org