

journal



DOWN'S
SYNDROME
ASSOCIATION

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Disclaimer

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

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Contributing to the Journal

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

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

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

Letter from the Chief Executive



Carol Boys

I'm writing this in the happy glow of the Lionesses' win in the UEFA Women's Euro 2022 championship. It seems very appropriate that this issue of The Journal has a big feature on the great plans for the future of our DSAActive Programme. We have ambitious and wide-ranging plans for the programme and are really excited to see it grow.

Our Policy work received a boost back in April when Chris Rees joined the DSA team as Policy Manager. There is a lot happening this year, including the Down Syndrome Act Call for Evidence being run by the Department of Health and Social Care. We contacted you about the Call for Evidence back in the summer and I can't emphasise enough just how important it is for as many people as possible to get involved. Please take a look at Chris' article on page nine if you want to know more.

Earlier this year we heard the sad news that Eric Nicholas had died. Eric was one of the key parent members in the Merseyside and Cheshire area and very much of a driving force behind his local group; he also served as a Trustee of the DSA. Eric was a volunteer parent contact for the DSA and for many years he took calls from new parents who had just received the news that their child had Down's syndrome. Eric worked as a Development Officer for the DSA and then later became one of our Information Officers. I remember Eric for his enthusiasm, amazing wit, great sense of humour and his ability to put people at their ease, he had no nonsense approach to life which made him a great asset to our organisation. Even now, we hear from families who spoke to Eric in the very early days following the birth of their child; they talk about just how much they appreciated his words of wisdom and support. Eric was a kind and generous man; generous with his time and empathy for those who just needed to talk. Our thoughts are with Gillian, Michael and the Nicholas family at this time.

Carol Boys, Chief Executive

Letter from Kate Powell



Welcome to the Autumn edition of The Journal.

In the My Perspective photography competition there are lots of amazing

photos. I found it very hard to choose a favourite. After looking for some time I found one I really like. I hope you will find your favourite and vote for it in the People's Choice.

What great work Our Voice is doing. Congratulations to all those who

earned their certificates.

There are lots of other very interesting stories in this edition.

I attend monthly Ambassadors Zoom meetings with DSI. Lucky me, I still get to talk to Robin and all of the wonderful ambassadors from around the world.

A reminder that Covid is still around, as I found out when I tested positive about a month ago. Luckily, I didn't suffer too much and recovered quickly.

So please everybody be careful and stay safe.

Kate

CONTENTS

NEWS

- 3 Pregnancy and Baby Support Group
- 3 Complex Needs
- 4 Our Helpline: there for you
- 4 Helpline stories: Benefits
- 4 New ways to access our online training
- 4 Behaviour information resource
- 5 My Perspective 2022
- 6 Memories & Stories: explore all the content on our website
- 6 Updated 'Congratulations on the Birth of Your Baby' leaflet
- 7 Our Voice

POLICY

- 9 Policy update

EDUCATION

- 10 Inclusive education for all

BENEFITS

- 11 Benefits when someone reaches 16

DSi

- 12 Meet Kami – The world's first virtual influencer with Down's syndrome.

OUR MEMBERS

- 13 Empowered artist Ella Evenson uses her artistic skills for good.
- 14 Better Together
- 15 Richard
- 15 Jubilee Garden Party Joy for David
- 16 Remembering Sammy

HEALTH

- 17 What do we know about COVID-19 and children with Down's syndrome?

DSACTIVE

- 19 Exciting Changes at DSAActive

DSENGAGE

- 21 DSEngage

FUNDRAISING

- 23 Generous support from some fantastic businesses

On the Cover: Joshua Birchall, 5 months and growing fast, gives us a gorgeous smile.

News

Pregnancy and Baby Support Group



We are continuing to hold Pregnancy and Baby Support Group meetings throughout the year, with a set of four fortnightly zoom sessions for each group of new and expectant parents. The groups have been well attended by mothers

and fathers with their babies from birth up to eighteen months old. We've had people join us from all over the UK. The number of expectant parents joining the groups has increased with all wanting to gain as much knowledge as they can before they meet their new arrival, which is really positive news.

Alongside Gillian Bird, Lindsay McCulloch, Abigail Harris, Jane McIlveen and Gwen Toner, who speaks about speech, language and feeding, Donna McEldowney has now joined our team. Donna is a paediatric physiotherapist in Northern Ireland and mum to a seven-year-old daughter who has Down's syndrome. The physical development session has been very well received by parents and has provided really useful ideas to work on in the early months of a baby's life.

You can look for dates of our future sessions and book online on our website downs-syndrome.org.uk/training/

Complex Needs

We continue to hold regular online meetings for parent/family carers who support a person who has complex needs (including autism spectrum condition). The meetings are facilitated to provide a supportive and friendly environment for participants to share information and experiences about key issues. Recent topics for discussion have included sleep, connection, preparing for change to routine during the holidays, and emotional well-being. Details of forthcoming meetings are available here: downs-syndrome.org.uk/training/

We use feedback from meetings to inform the direction of DSA's work and to develop new resources and articles for the Journal. Discussion at a recent meeting about recognising well-being led to the production of *'Well-being – What does it look like and what to look out for?'* for supporters and *'What is well-being?'*, an easy read resource for people who have Down's syndrome. These are now available at our website here: downs-syndrome.org.uk/EmotionalWellBeing/

Similarly, we will be using, and expanding upon, feedback from families about what connection means to their loved ones who have complex needs to inform the development of a new DSA resource.

Our complex needs and autism closed Facebook group continues to develop and grow as a place of support and information sharing. Join the group here: facebook.com/groups/

We hope to refresh the information at the complex needs and autism section of our website in the near future.

Our Helpline: there for you

The 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.

Our Helpline (which operates Monday to Friday, from 10am-4pm, is staffed by the DSA's information team and specialist advisers.

On average, we receive approximately 10,000 enquiries a year to the Helpline.

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 and we are able to offer rights-based information and advice.

We can call upon the specialist advice of colleagues and advisers. These include speech, language and communication, benefits, adult social care, education, health, development, additional diagnosis and behaviour, for example.

Calls and emails come in about all aspects of life today for people who have Down's syndrome and their families. Enquiries come from a range of people; from new families who have just had a baby asking about the start of life; to older family carers who have spent a lifetime caring and who are now making plans for when they will no longer be able to care for their

adult sons and daughters and wish to see them safely settled.

We also receive calls from those who are undertaking pre-natal screening and testing.

It is true to say that for many families their relationship with the Helpline is a lifelong one. We know parents who have regularly called the Helpline; initially when their child was born and then as they grew up and reached key life stages. Some families just like to check in and let us know how they are getting on. For some, it is literally a trusted lifeline in times of worry and difficulty.

Where required, we provide regular ongoing telephone support and advice to individual callers.

Helpline stories: Benefits

'My new baby who has Down's syndrome has arrived. Am I entitled to any benefits?'

This is one of our most asked questions and the answers, although similar, vary. We advise on an individual basis.

The general concerns tend to be work related, *'Should I go back to work? Should I take a career break? Shall I change my hours? Is there help with funding childcare?'*

Although we cannot ultimately decide which path is best for you and your family, we can discuss the options available to you, which gives a clearer picture and peace of mind.

'My Tax credits are due to end as my son is almost 20, what can he claim instead?'

Around this time, there are various benefit options and some extra potential discounts such as council tax disregards which are overlooked by many. We can advise on the best ones for your family circumstances.

Benefit procedure and law changes frequently. We have a wide range of information available in the benefit section of our website. The information is updated every April with the benefit increases and throughout the year as things change. Benefits can be complicated and confusing, and for many people, this is the first experience of claiming them. That is what we are here for so please give us a call.

You can ring Helen to talk about all DWP benefits from birth to old age. Helen helps with maximising benefit entitlement, claims, reconsiderations, appeals, blue badge help and funding signposting.

'Thanks so much for your prompt reply. The information you have provided is of enormous help.'

Thank you to everyone who donated to our Benefit Lifeline appeal earlier in the year. Your generosity continues to keep this vital service open to all.

Go to page 11 to read the latest benefit information.

'I just want to message to say yet again another thank you for all you have done for us regarding our situation. You've given our family continued support and there's definitely been a positive outcome. I couldn't have managed this without the help from yourself and I am forever grateful for what you have done. People like you certainly sustain faith in humanity and if the world had more people like you then what a wonderful world it would be.'

New ways to access our online training

Our popular range of 24 live online training events continue to allow parents, carers and professionals to access our expertise wherever they are. The subjects go from birth to old age, cover different ages and stages of education and many types of transitions and changes. You can also now watch Pay Per View, on-demand recordings of many of these sessions whenever it's convenient for you.

You can also access recordings of many of our free online events, many with guest speakers, from our YouTube channel.

Go to downs-syndrome.org.uk/training/ for all the details.

Behaviour information resource

We have produced a new resource *'Using the model of positive behavioural support for change for children age 5 to 17 years'* which is free to download at our website here downs-syndrome.org.uk/PositiveBehaviouralSupport/. This resource looks at how to understand problem behaviours as well as how we can manage and change them.

My Perspective 2022

We're thrilled to be holding the *My Perspective* photography competition again this year. Entries closed in the summer, the shortlist has been selected and we'll soon be opening up the Peoples' Choice vote...your chance to pick one of the winning photographs.

The winners will be revealed at an awards event at the Langdon Down Centre on 3 November. You'll find all the details in the Winter Update in December.

Here's a random selection of some of the amazing photographs submitted this year.

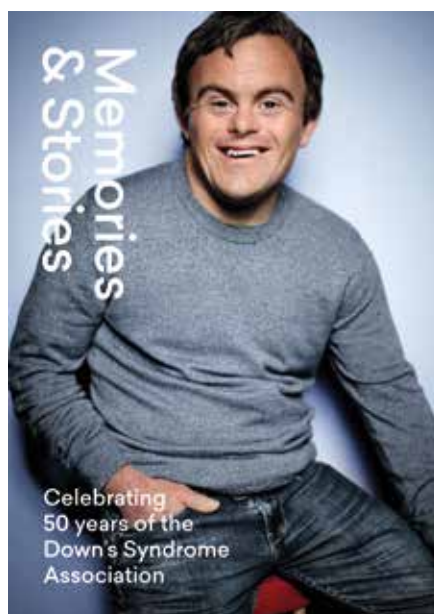


Memories & Stories: explore all the content on our website

If you weren't able to come down to the Langdon Down Centre to one of our Open Days, all the Memories & Stories photographs and oral histories are still available to enjoy on our website.

The project celebrates what the DSA and the wider Down's syndrome community has achieved in the last 50 years...and marks where we are now with a multimedia collage in words, audio and photography.

Find it all at downs-syndrome.org.uk/MemoriesAndStories/



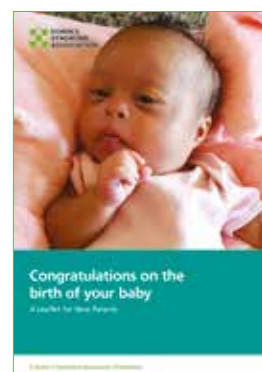
Updated 'Congratulations on the Birth of Your Baby' leaflet

Earlier this year we published an updated version of our 'Congratulations on the Birth of your Baby' leaflet.

This publication forms an important part of our new parent pack. We send these out to all new parents who contact us, and the resources are available on our website downs-syndrome.org.uk/you-and-your-baby/ for anyone

to download as well. You'll also find some wonderful stories from new parents on the same page.

We're so grateful to everyone who shares their stories and photographs with us, and we'd like to say a particularly big thank you to the parents of all the little ones whose photos make the 'Congratulations' leaflet such a joy to look through.



Our Voice

What have Our Voice been working on?

The Our Voice team is a group of people who have Down's syndrome who tell the DSA what they think. Our Voice contribute to the work the DSA is doing, and work together for change.

Earlier in the year, the Our Voice team celebrated World Down Syndrome Day with an 'Inclusion Party', investigated

the Good Lives framework, provided ideas to a film company, wrote poetry, discussed the Down Syndrome Act, and said farewell to our colleague Robin, who we wish well in his role at Down Syndrome International.

We are currently contributing to a campaign hosted by Learning Disability England, called *Good Lives: Building Change Together*. The Good Lives framework brings together people's

thoughts about what it will take for everyone who has learning disabilities to be able to live their [#GoodLives](#).

As Catherine said, *'This is a campaign we can help with to make life better for all of us with Down's syndrome.'* Joe said, *'We need support in place to make sure we can have a good life.'*

There are six chapters. Here are some thoughts from Our Voice about each one.

| Chapter 1: A home | Chapter 2: Communication | Chapter 3: The right support |
|---|--|---|
| <p>What is important to you about home and family life?</p> <p>Lorni: <i>I enjoy my family and home life. I love my dog and being with my mum. I like all my home comforts like reclining sofas. Sometimes I write lists of what I want for my flat, ready for when the time comes [to move out].</i></p> <p>Lindsay: <i>I love my family life. I have got my nieces and nephews and I am not far away from my church – I can go there on my own.</i></p> <p>David: <i>Mum and Emma and Luke support me. I like films and Taekwondo.</i></p> | <p>What is important to you to stay connected with others?</p> <p>Katherine: <i>Having my best friend – she is my Good Life. I support her, I am her biggest supporter. Actions speak louder than words.</i></p> <p>Molly: <i>I do contact my family and it's quite a nice feeling. And my friends as well. We contact by WhatsApp group and it's great to share with my cousins, aunts and my sister.</i></p> <p>Emma: <i>I use text messages, family WhatsApp, send photos of what they are doing, emails, tablet and Facetime. I use the landline as well. I have mum, sisters, nieces, loads of friends and loads of people I don't see any more so I miss them.</i></p> | <p>What does the right support look like to you?</p> <p>Joe: <i>It's a form of support for our voices to be heard in any way possible. It is the heart of it all and being heard is everything.</i></p> <p>Angus: <i>I live independently but don't need support. If I needed help I would go to Services or the DSA. People with learning disabilities are different – not everyone needs the same support.</i></p> <p>Harshi: <i>To feel included, not isolated, and have someone to talk to. Sometimes I need support to talk to other people and to my friends. If I got less support I would be worried.</i></p> |
| Chapter 4: To love and be loved | Chapter 5: Advocacy and self-advocacy | Chapter 6: Employment |
| <p>What is important to you about relationships?</p> <p>Emma: <i>I have got a relationship which started at school and I live with my boyfriend. He helps me with the washing.</i></p> <p>Catherine: <i>Having good relationships is a good thing to have in your life. Parents, relations with family, or could be a girlfriend or boyfriend. There are different types.</i></p> <p>Joe: <i>What most people don't know in reality is that it is a bit more of a struggle for people with Down's syndrome to find that romantic relationship as so many things get in the way.</i></p> | <p>What is important about speaking up for yourself?</p> <p>Robert: <i>Important to me is the world, health, social media, learning together, Zoom, and the government.</i></p> | <p>What is important to you about contributing to society?</p> <p>Sam: <i>My job is important because you earn money to live and pay your bills and pay taxes as well.</i></p> <p>Samuel: <i>Work gives me energy, power, and human rights.</i></p> |

At the end of the session, Lindsay said, 'I think everyone has done really well today'.

We'd like to say a big thank you to all the members of Our Voice. Here are just a few of the team who come to the Weekly Check Ins. Their certificates recognise all their hard work in 2021.



Policy update

Chris Rees, who joined us as Policy Manager in the spring, shares an update on our Policy work...the work we do to try and influence changes at a national level across all the key issues we know affect children and adults who have Down's syndrome.

We undertake our policy work in many different ways; a lot of it involves keeping an eye on what is happening in Parliament and in the devolved administrations and then responding appropriately to any new decisions or proposals.

We also link in with ministers, MPs, MSs, MLAs and civil servants across the political spectrum and the different ministries to engage and discuss key issues directly. At any one time there are always numerous government consultations open on all kinds of subjects, and we always aim to respond to any that affect people who have Down's syndrome.

In the first half of the year, we have responded to over ten such consultations including The Human Rights Act reform, NICE Vaccine uptake, Welfare Benefits claims and the Welsh Government Learning Disability Action Plan – all these can be found on our website.

We are also members of a number of national networks and campaigning groups, including the Disabled Children's Partnership, the Special Educational Consortium, the NHS Digital Flag network and the Learning Disability and Autism Partners. Being part of these groups enables us to discuss key and shared issues, and promote our priorities as part of a wider network. As we continue to face a period of change across a number of policy areas, our involvement in these networks is vital.

We continue to aim to provide accurate and up to date information to our members on our policy work through webinars, policy updates and briefings. Keep an eye out on our social media and website for news on upcoming policy events, and new information and resources.

As I write, in early July, we are in a time of great change across a number of areas of national policy:

Education – The consultation for the SEND review (England) will close at the end of July, and so by the time you read this we may be closer to finding out what specific actions the government may want to take forwards on this.

The SEND Review aimed to address problems with the system of special educational needs (SEN) and disabilities, but there have been some concerns about how the rights of families may be impacted by the Review. Parliament is also working its way through a new Schools Bill which will become law soon.

Health – The Health and Care Act has recently passed, with a number of implications, not least on the development of Integrated Care Boards (ICBs). We are also anticipating a refresh of the 10 year NHS Plan, and the NHS's COVID recovery plan – 'Building Back Better'.

Social Care – In June the Independent Review of Children's Social Care submitted their report to government. We fed into this directly and through our work with various networks, and we await a response from the Government in Westminster on the recommendations made by this report.

And then, in England, we have the Down Syndrome Act. We know that this piece of legislation has created high hopes and expectations amongst many of our members, many of whom continue to struggle to access the right support from local services.

In recent months one of our priorities has been to ensure our members are fully informed on what this Act, and the guidance it creates, actually does. We developed updates and briefings and held a successful event with SEND barrister Steve Broach and IPSEA legal staff to discuss the legal implications of the Act.

We will continue to work with the civil servants leading the consultation on the Act's guidance to ensure whatever is produced is meaningful, evidence based and effective.

We know that achieving meaningful changes to policy at a national level is never straightforward, but it is an important part of our role here at the DSA.

You can find out more about all of the above subjects on the policy section of our website, and we always welcome feedback on any issues where we may need to provide more information.



To find out more about any aspect of our policy work, please contact us at any time on policy@downs-syndrome.org.uk

Stop press!

The Down Syndrome Act Call for Evidence is now open and will run until 8 November 2022. Find out more and how you can #GetInvolved and make your voice heard on our website: downs-syndrome.org.uk/DSActCallForEvidence/

Inclusive education for all

By Chris Barnes, Inclusive Education Officer, Down Syndrome International

Thanks for reading this short summary of our UK Inclusive Education campaign 2021/22!



In some ways the UK education system is a fantastic, world-leading provision, that is the envy of many, many countries. I personally feel grateful to have been born and educated here, and to be able to send my children to school for free. As an employee of the DfE for many years, I'm also aware of the good conditions in which I was able to work. However, there is still much work to be done in our education sector for it to be classed as inclusive for all children and young people.

Inclusive education can be defined as being accepting and effective for all. An inclusive education system allows for all children to be educated at their local school, alongside all other children. This would mean that children with disabilities could be taught alongside children without disabilities in all cases. So, you can see, we are a way off achieving that in the UK at the moment.

Research

In September 2021, I began some basic research – interviewing as many people involved in education as I could, while getting up to speed with as much current literature and research as I could lay my hands on. Through a process of listening and questioning, a picture of the UK education system offer – for people with disabilities, including Down's syndrome, and those without – began to take shape. People with lived experiences including parents, self-advocates, and educators shared their stories and opinions on the theme of inclusive education.

This process was, and continues to be, ridiculously enlightening. There have naturally been similarities, overlaps, and concurring views, alongside the polarised and disparate. What is clear is that for inclusive education to become more than a concept, all stakeholders (from government policymakers to lunchtime supervisors) must work together more cohesively under far less ambiguous guidelines.

The Campaign

We formulated a set of concise key messages, tailored to a variety of stakeholders within the education hierarchy. These messages became our campaign, and we shared one each week in a blog post, between January and August this year. Our aim was to inform and bond together the people involved (directly or indirectly) in the education of learners with an intellectual disability, including learners who have Down's syndrome. The blog posts were our advocacy campaign and included pertinent information about how the education system can develop and, hopefully, become more 'inclusive' over time, for the benefit of all children and young people.



Alongside the blogs we hosted two popular webinars on the theme of inclusive education.

The first was designed for teachers and staff working with learners with an intellectual disability; the second was for parents – sharing current educational thinking and advice on the inclusion of children with disabilities. We were proud to welcome people from all over the world to both of these events.

Future work

We are working on a resource platform for teachers and parents, where useful information on the theme of education can be easily accessed and shared.

Our next project will be building a set of case studies detailing the inclusion of children who have Down's syndrome across a wide age range (4-16). These case studies will go into the detail of how schools can actively and effectively include a child with Down's syndrome in the mainstream, alongside the reality of the challenges and barriers.

On first glance this is not something new or particularly innovative – children with intellectual disabilities should be, can be, and are included in mainstream. 50% of children in England with an EHCP are currently in a mainstream setting.

These case studies will serve as advocacy tools for those people who are starting out, or experiencing major barriers in their individual circumstance, whether they are parents or teachers.

Thanks for reading – please get in touch if you'd like to hear more. You can email me on Chris.barnes@ds-int.org and catch up on all our blog posts on the DSA website here: downs-syndrome.org.uk/ InclusiveEducationForAll/

Benefits when someone reaches 16

You can make a contribution credit only claim for new style Employment and Support Allowance (NESA) without affecting family benefit.

From 16, the young person can make a 'contribution credits' claim for new style ESA. There would be no benefit payable which means child benefit and child tax credits for that young person are unaffected in their parents claim.

A national insurance credit will be made and the Work capability assessment - WCA, carried out in readiness for being able to make a claim for Universal Credit (UC).

The importance of claiming credits at 16

Those assessed as having limited capability for work related activity' (LCWRA) should qualify for an extra amount in their UC in the first payment period, rather than having to wait 3 months into claiming (when the WCA is done through UC).

In addition, they will immediately be able to take advantage of the work allowance within UC if they have limited capability for work (LCW) or work-related activity (LCWRA).

This work allowance means monthly earnings of up to £573 per month (no housing payment) or £344 (if receiving housing payment) are disregarded before the earnings taper is applied. As of June 2022, this taper is a 55p reduction in the UC amount for every £1 earned.

How to make a credits only claim for NESA

To make the credits only claim for NESA, you can contact your local job centre. You will need a fit note. From 1st July, these notes can be issued by nurses, occupational therapists, pharmacists, and physiotherapists as well as your GP.

Universal Credit

Universal Credit changes from mid December 2021 meant that new claimants who are students and who receive education of at least 12 hours a week, no longer qualify for UC, unless their work capability assessment (WCA) has been done before they commence a course of full-time education.

This results in a benefit shortfall once the young person leaves their parents claim (usually the September after their 19th birthday) if the young person is unable to make a claim for benefit.

UC – Can your course be disregarded? Check.

A qualifying young person is treated as receiving education unless taking part in a traineeship or relevant training scheme. This is education or training designed to assist a claimant to gain skills needed to obtain paid or better paid work.

A traineeship example would be a course funded by the Secretary of state under section 14 of the Education Act 2002 or Chief Executive of Education and skills funding which lasts under 6 months and provides training in work preparation from age 16.

Check to see if UC will accept the life skills course as something other than education. If so, your UC claim may be successful.

Savings

UC is means tested. Check savings before you claim. Any savings in the claimants name under 6K will not affect benefit. Anything over 16K would mean UC is not payable. Between these 2 amounts, benefit is reduced on a sliding scale, a £1 reduction for every £250 or part thereof over 6K.

New Easy Read guide to benefits for those over 16 years old

Earlier this year we created a new easy read guide about the benefits that they are available to be claimed by those aged 16 or over.

To find it go to downs-syndrome.org.uk/Benefits and scroll down the page.



Meet Kami – The world's first virtual influencer with Down's syndrome.

In partnership with Forsman & Bodenfors Singapore, Down Syndrome International (DSi) has launched the world's first virtual influencer with Down's syndrome. Kami, short for Kamilah, which means perfection in Arabic, has been created to make the digital world more inclusive. She has been launched on Instagram and can be found under the handle @itskamisworld. Instagram currently has over 200 virtual influencers, but none have any form of disability until now!

The rise of the metaverse and web3 is still relatively new to many people, but it is fast becoming a space that cannot be ignored. DSi wanted to make sure people with Down's syndrome are included as early as possible. They see Kami as the perfect starting point in a world that has so far been created for only the 'perfect' few.

'In a world filled with pixel-perfect virtual models, creating Kami is a way to completely reframe Down's syndrome in the online space,' say creatives Rachel Kennedy and Firrdaus Yusoff of Forsman & Bodenfors Singapore.

'We want to make it impossible to ignore Kami and everything she stands for. As we get to know her, Kami's true potential will depend on how the world embraces her in her virtual form.'

Kami's image has been formed using over 100 photos of real women with Down's syndrome worldwide. By using machine learning, Kami is an authentic and representative 3-D character. Kami's visual producer is Cameron James-Wilson CEO of the Diigitals.

Generating the initial concept of Kami from an algorithm, more than the touch of a human hand, eliminated any notion of unconscious beauty bias in the character creation process,' James-Wilson says.

Human beings cannot exist in the metaverse, so using a person with DS instead of Kami is impossible. However, Kami's Instagram content is created by collaborating with real people who have Down's syndrome, known as 'Kami Contributors'. What Kami says, where she goes, and what she likes comes directly from them.

Also, Kami will spotlight talented people with who have Down's syndrome and has already created paid employment opportunities for the community.

Russell Watkins from DSi is overseeing the project.

'Kami should be for everyone, and I'd love for her to be someone any young woman can look up to,' Russell says. *'We hope to see her living her digital life without being challenged for why she's there.'*



Be sure to follow Kami on Instagram and join her on her mission to make the digital world a more inclusive place.

Empowered artist Ella Evenson uses her artistic skills for good.



Ella is only 13 years old but has been painting and drawing for as long as she can remember. Never one to just settle for an easy life, Ella is always keen to try new techniques and improve her skills. She is a deft hand with acrylics, loving the abstract styles of David Hockney and Patrick Heron. Her piece Sweet Pink is a perfect example of how Ella uses colour and texture to create vibrant and really uplifting compositions. Ella also uses watercolours and alcohol inks, enjoying experimenting widely (and sometimes wildly!).

'I like to try new things. It's exciting.'

Ella is determined that her skills should be used for good. She has created and sold work for a broad range of charities, including the DSA, the Australian Bush Fire Crisis and the NSPCC. Ella has a wonderful, can-do attitude and is a great example of how much can be achieved when you put your mind to it. Ella is not one to be limited, to be told what she can/can't, should/shouldn't do, instead she is someone to break the mould and forge her own path.

Ella's inspirational approach has not gone un-noticed and earlier this year she was asked to lead a number of art sessions for Diff-Ability online. This has been a great opportunity for Ella to share her own learnings and encourage others to pick up a paintbrush. This has given her a great boost in confidence and allowed Ella



to meet a host of new people from the disability arts community.

Ella's latest endeavour is to join the Art Rabble, a social enterprise which sells framed art prints and greetings cards by artists with disabilities.

The aim is promote the skills of artists with disabilities, challenge limiting

stereotypes and liven up people's walls. All things which Ella is passionate about.

'I feel very happy and proud that I have started selling my artwork. It means my determination and love for painting is in lots of people's homes.'

To support Ella and see more of her work, please visit art-rabble.org.

Better Together

By Victoria Bowman



My name is Victoria and I am 37 years old and I have Down's syndrome. I have always used the saying 'I am more alike than different'. I live in a supported living house in Darlington and I love it.

My sister Emma got me thinking about Ibiza a lot as she had visited the island with her friends and they told me about an amazing beach club there called Ocean Beach. I really wanted to go one day...it sounded amazing, music, a DJ playing, cocktails, dancing. Just up my street.



In April 2019 a group from Darlington including me and my friends and support staff had a short trip planned to go to Ibiza to celebrate one of the staff's big birthdays.

Little did I know that my sister Emma had actually been in touch with the gentleman who owns Ocean Beach, Wayne Lineker, Gary's brother, to ask if

there was any chance as a special treat he could let us have a look around the club with me and my friends who also have Down's syndrome.

It was April and the club wasn't actually even open.

To my surprise, Wayne said 'Of course'!...it was no problem at all and that he'd open the club specially for us and the support staff and treat us to lunch in his restaurant.

I was totally shocked, overwhelmed, excited. I couldn't believe it. I was so happy.

The big day came and we were met with champagne on arrival and given a full tour of the club. I was on cloud nine. Wayne himself took us around the club personally. On the way to the restaurant I chatted with Wayne and told him how I loved rapping and he asked me if I could do him a rap, so I just gave it my best shot and it turned out to be brilliant. I could tell Wayne loved it. I love drama and acting and music and I just couldn't help myself to show him what I could do.

We all enjoyed a lovely three course meal in his restaurant and drinks all paid for by Wayne and we left on a total high.

For me this was the start of our amazing friendship.

We stayed in touch, me, my sister and Wayne and would message each other about what we were up to and he even came all the way up to my home town to visit me and my family. Wayne loved my rapping and he said he was going to try and make me an international rap superstar, and he said he wasn't joking.

In November of 2020 I travelled to London with my sister Emma to record a song that I would actually be rapping and working on. I have to say I felt like a complete superstar...I was loving every minute of it. I got to meet others working on the song who welcomed me into the team with open arms and it had the perfect title – 'Better

Together'. The title says it all. We are all better when we are together no matter who we are. I sing along with Clark King. We were going for it, we decided we were actually going to release this song and make a music video along with it and all proceeds will go to the Down's Syndrome Association (DSA).

Fast track to September 2021 and Wayne arranged and paid for my mam, sister and two best friends Emma Watson and Penny Watson and their support staff to stay in Ibiza whilst filming the video for the song 'Better Together'. All I can say is it was like living the dream. I had the best holiday ever and we filmed all over the island. It really was so much fun. I can't wait to see the completed song and video.

Wayne even took time out of his busy schedule to see me in my drama group's show in November 2021. The group is called Northern Stars. We really have a strong friendship and he's just like family to me now.

'Better Together' was released on World Down Syndrome Day (21 March 2022) and all the proceeds will go to the DSA. Please take a look and a listen. I promise you it will be amazing.

<https://youtu.be/wrreogusQK4>



Richard

Hi! My name is Richard. I'm 38 years old and I have Down's syndrome.

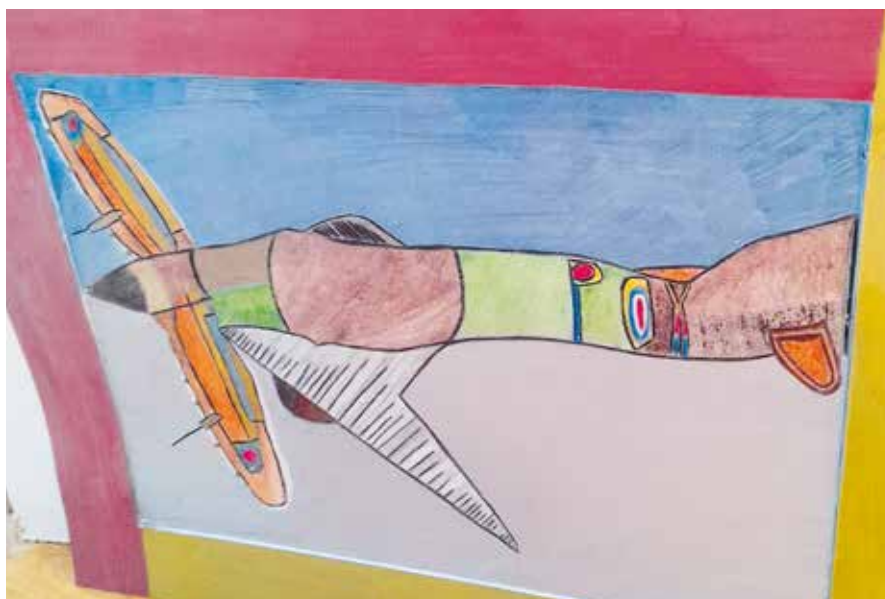
I have three jobs. I work for Homebase and a local garden centre and a cafe.

I live with people with mixed disabilities in shared independence flats.

What I do for fun is this:

I enjoy writing books, artwork, word search, and scrap art where you take silver of the art.

My best thing I enjoy is going to seaside, out in pubs and to the cinema, meals out, art galleries and reading books.



Richard sent us this photograph of one of his artworks.



Jubilee Garden Party Joy for David

David, who's 38, joined West Mercia Police in September 2019 as a volunteer after registering with our WorkFit programme. In June David attended the Queen's Platinum Jubilee – Worcestershire Garden Party, hosted by the Lord Lieutenant of Worcestershire, in recognition of his outstanding service in his role. David's written in to tell us all about his amazing afternoon:

I was invited to a wonderful Garden Party at Hartlebury Castle in celebration of the Queen's Jubilee. We arrived about 3.30 and had to check our name on a very long list before we could go into the Gardens. Across the lawns we saw the big castle building and a large

white marquee where the teas were waiting, and a smaller tent for the choir and a band to entertain in. At 4pm the Lord Lieutenant gave a speech and then everybody was talking. We met our MP and the Deputy Chief of West Mercia Police and one of my old

cub leaders and several other people I know. I loved the tea especially my favourite chocolate brownie. We looked around the castle and outside at the big pond. Soon it was time to leave and I was given a little tree to take home and plant.

Remembering Sammy

The DSA's WorkFit programme has been operating since 2012 and over the years, everyone we have met and supported has left a lasting impression on the team and no-one more so than a young lady called Sammy.



Samera Uddin registered for WorkFit in August 2016 and started a permanent paid job at the Hilton London Metropole in London as a Commis Chef on 27 March, 2018.

From the first day, Sammy was a popular and hard-working member of the team, impressing everyone with her skills in the kitchen and her beautiful smile. Her success in the role paved the way for other people

who have Down's syndrome to join the workforce at the Hilton London Metropole with support from WorkFit. In total, the team there, inspired by Sam, have welcomed a further four colleagues in the last 4 years. Two of them, Brogan and Shomari, are still there in permanent positions. Brogan and Sam developed a close friendship and supported each other both as great friends and dedicated colleagues in the workplace.

Sam passed away on 24 January, 2022 and her loss has been keenly felt by her friends and colleagues at Hilton London Metropole and WorkFit. However, she will continue to be an inspiration in so many ways and her beautiful spirit and love for life will always stay with us.



Gone but not forgotten.

We were deeply saddened to hear of Sam's sudden death earlier this year. We're so honoured that Sam's sister, Roxanna, ran the Cardiff Half Marathon in memory of Sam in March and chose to fundraise for us.

Roxanna did amazingly well and has beaten her fundraising target. On her JustGiving page ([justgiving.com/fundraising/roxyuddin](https://www.justgiving.com/fundraising/roxyuddin)), she says:

'It is impossible to come to terms with Sammy no longer being with us. She was the sweetest, most loving, and wittiest person I had ever known, and I feel so lucky to call her my sister. Sam was the centre of our family, and we know life will never be the same without her. She touched so many people's lives and will remain in our hearts forever.'

Our deepest condolences go to all Sam's family and friends.

What do we know about COVID-19 and children with Down's syndrome?

By Laura Nixon, Child Health Research Assistant and Prof. Monica Lakhanpaul, Professor of Integrated Community Child Health at UCL Great Ormond Street Institute of Child Health

The COVID-19 pandemic has impacted us all in some way or other, but the extent of the impact remains to be seen. This is especially true for those who are often overlooked in research and policy, such as children with learning difficulties. Despite many researchers taking responsibility to collect the evidence to inform policymakers (such as influencing vaccination strategy), more needs to be done if we are to overcome the challenges that children who have Down's syndrome have faced. As is the case for all children, the health impacts of having COVID-19 are considered to be less for children who have Down's syndrome than adults. However, many children with Down's syndrome were still more vulnerable to catching COVID-19, with many being in contact with carers, in care homes, and/or finding it difficult to stick to safety recommendations like wearing masks and social distancing. This is why it is important that we consider what research was done, what evidence was collected, how this will impact children, and what researchers need to study further. This article will look at what we currently know about COVID-19 and children who have Down's syndrome.

Impact of getting COVID-19

As with the general population, getting COVID-19 will affect different people with Down's syndrome in different ways. Some won't have any symptoms, while others may be affected very severely. How serious it is can often be due to other factors in a person's life, such as weight, ethnicity, lifestyle (e.g. smoking) or other health conditions. It is also affected by the age of the person in question as well as any other health condition they have (for example, epilepsy or trouble breathing).

Adults with DS

Research shows that people who have Down's syndrome are more likely to be hospitalised than those without Down's syndrome, and if hospitalised they have a higher risk of medical

complications and death. Just as in the general population, the risk increases with age; however, the risk is more severe at an earlier age in people with Down's syndrome, with a significantly higher risk of complications after age 40. However, adults who have Down's syndrome generally show the same symptoms as other adults, although are slightly more likely to have confusion and less likely to have joint/muscle pain or nausea.

Children with DS

Children who have Down's syndrome are less at risk than adults but are more likely to have symptoms and complications than other children.

Covid-positive children with Down's syndrome are more likely to have a cough, fever, nasal signs, or shortness of breath than children without Down's syndrome, perhaps due to their higher rates of pre-existing breathing problems. In a similar way to adults, children who have Down's syndrome who were hospitalised with COVID-19 were found to be more likely to have worse outcomes than children who did not have Down's syndrome who were hospitalised while COVID-positive. They are more likely to get pneumonia, Acute Respiratory Distress Syndrome (ARDS) and acute renal failure.

Most children with COVID-19 will only have mild cases, but if you are concerned it is important to call 111 to see if the person in question requires medical attention or 999 if urgent medical care is needed.

Impact of the pandemic restrictions

In this section we look at what impact these restrictions have had on children, including findings from our own study on children under 11 in the UK. Our team at University College London partnered with the Down's Syndrome Association and Trisomy 21 Research Society to look at the impact of the pandemic on children under 11 years old who have Down's syndrome in

the UK. They did a survey of 241 parents/carers of children with DS to see the way that lockdowns and the stress of the pandemic had affected their lives. The study focused on six topics: Education, Healthcare access, Behaviour, Mental Health, Physical Health, and Family life.

Mental Health

People who have Down's syndrome experienced increased rates of depressive symptoms and social withdrawal than before the first national lockdown, as well as a decrease in ability to function in daily life.

Studies also show an increase in anxiety in children who have Down's syndrome, mostly related to feeling isolated and concerns about having less social contact. Outbursts of anger/aggressive behaviour also increased during lockdown but were shown to decrease as restrictions eased. In our own study, parents also reported a change in their child's mental health and behaviour. Most parents believed that their child's emotional wellbeing had got worse, with a large increase in children presenting with signs of aggression and crying. They also reported that this had put a strain on family relationships. However, it is also important to note that not all experiences of the pandemic have been negative, with some children getting more time outside, sleeping better and enjoying the additional time at home with family.

Education/development

Children who have Down's syndrome have scored lower on cognitive tests after the pandemic regardless of whether they have had COVID-19. Parents who were given online coaching on how to support the child's development scored much better than families who had not had the support, but still scored worse than they did before the pandemic. Similar studies also found other online

educational support programmes for parents successful.

Over the course of the pandemic, many children who have Down's syndrome had to switch to remote learning for school. In our study, parents believed that remote learning had a negative impact on children with Down's syndrome. Half of parents of children who continued school online felt that their child did not progress with their learning and over most felt they were missing out on key learning activities. Most also believed that missing out on after-school activities had a moderate-large impact on their child and that the lockdown had caused their child's social skills to deteriorate.

This tells us that lockdown has not just delayed their education and developmental progress but that it could have had a negative impact on their current ability. Going forwards it is important that families are given the right tools and support to help their child reach their full potential.

Physical Health

Our own study also looked at how the pandemic had affected children who have Down's syndrome's access to healthcare and therapies. Parents said that almost 90% had healthcare appointments delayed or cancelled, almost half said that their child's regular therapies did not continue, and only 1.6% had continued regularly in person. Almost half of those awaiting surgeries had them cancelled due to COVID and many were delayed. Unsurprisingly, over half of those parents were worried about their child's health as a result and a third of all parents have seen a direct increase in health issues.

Knowing that so many children have had these problems accessing care, we can see the importance of advocating for children who have Down's syndrome. We need to ensure that they do not miss further health assessments so that this does not have a long-term impact on their health. Regular reviews with the medical teams will be important for getting children back on track.

Vaccines

There has been a lot of misinformation about the COVID-19 vaccines, so it is sometimes hard to know what to

believe. Though we do not have data from vaccination trials specifically about children who have Down's syndrome, we do have information on how the vaccines affect adults with Down's syndrome.

Research shows that the vaccine is safe and effective at reducing severe cases of COVID-19 for people who have Down's syndrome. Having Down's syndrome does, however, put you slightly more at risk for mild side effects from the vaccine than the general population, probably because people who have Down's syndrome are more at risk of health problems in general. These risks are minimal compared to the risks of having COVID-19. After reviewing the evidence, the UK Government, the NHS, and the Down Syndrome Medical Interest Group all recommended that people (children and adults) with Down's syndrome get the vaccine. As children who have Down's syndrome are considered clinically vulnerable, they are offered slightly different vaccination schedules. Children 5-11 years old with Down's syndrome only need to wait 8 weeks between their 1st and 2nd dose (instead of 12) and children aged 12-15 are recommended a third booster dose (instead of only two), while people over 16 who have Down's syndrome also have access to all three doses. A 4th booster jab is currently not available to people with DS unless they have additional conditions that mean they have a severely weakened immune system.

If you have concerns about the safety of the vaccine for you or your child, speak to your GP.

Moving Forward

The new strains of virus have been shown to have milder symptoms in the general population, but they also spread more easily. Even though there are no more government rules to prevent COVID-19, taking precautions when in a crowded space is still recommended to protect you from getting the virus. Wearing a mask, social distancing and washing your hands frequently are effective prevention methods, especially when there is an increase in cases.

Overall, although there seems to be an increased risk of illness for people who have Down's syndrome, the severity will depend greatly on the level of health issues that they have to begin with (e.g. heart or breathing problems). Parents should be encouraged to speak with their GP/ paediatrician if they have any concerns as regular communication between families and healthcare professionals is key to supporting a child who has Down's syndrome.

Moving forward, we need to focus on how to enable children with Down's syndrome to recover not only from the physical effects of Covid-19 but also the damaging emotional, educational, and social effects of lockdown so they can go on to achieve their full potential.

Further Reading

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Exciting Changes at DSActive

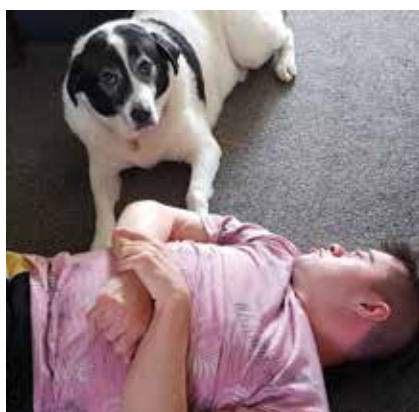
It has been a busy and exciting time for the Down's Syndrome Association DSActive Programme. Here we catch up with Kate who has been working on the programme to learn more about how it is evolving and improving to facilitate more opportunities for people who have Down's syndrome to be physically and mentally active.



Matt and Jess – best friends together enjoying the end of season Trophy Presentation at Burton Joyce.

For over 15 years, DSActive has introduced children and adults to opportunities to participate in Down's syndrome specific sport sessions, mostly football, tennis and cricket. These sport sessions gave the participants the chance to keep active, helping them maintain good physical and mental health. When the Covid 19 pandemic caused the programme to pause it was a great opportunity to reflect on the successes to date and to review how opportunities to evolve and improve might be developed.

The review identified the need to widen the reach of the programme, and to support opportunities to participate and be included in activities that are not described as 'sport'.



Cai and Joseph the dog enjoying Guided Meditation during DSEngage Pilates Plus

The review also looked at how activities are made available to children and adults who have Down's syndrome. Providers typically run non-disability ('mainstream'), pan disability or pan impairment, learning disability or disability specific sessions. In the past, DSActive has been associated with Down's syndrome specific sessions.

Going forward, the **Down's Syndrome Association DSActive Programme** will be supporting and facilitating opportunities for participation and inclusion within the communities that children and adults who have Down's syndrome live and work in.

We will support a far wider type of activity, provided within a more diverse type of session. Our Partner Organisations, who provide Down's syndrome specific sessions, will be joined by a wide range of other partners.

Activities could include aqua-aerobics classes, craft classes, gardening clubs, cycling clubs, Brownie groups, Drama and Film Clubs, to suggest just a few. The potential reach of the DSActive Programme is huge! We will continue to support national festivals and work with bodies such as Sport Governing Bodies, the NHS, and local authorities and we will be extending our partnerships, working for example with governing bodies associated with physical and recreational activities.

Whilst we know that there are many activity and session providers already doing great work to enable participation and inclusion, this is not always the case. Often it is a lack of knowledge and understanding that creates a barrier. DSActive will be able to support and facilitate by plugging into our Helpline team of Information Officers and specialist advisers and its expert training and education provision. This is a really important and pivotal part of the evolution of the programme and why it is important

that the Down's Syndrome Association is acknowledged within the wider title of the Programme.



Zoe and her dad on their tandem

As part of the DSActive review, the online DSEngage programme will continue to provide a range of physical and creative activities creating opportunities to be both physically and mentally active. Popular regular weekly sessions anchor the programme, and special events and seasonal sessions are very well attended too. The continued popularity of the sessions demonstrates the ongoing demand for alternative means of participation and inclusion. The ease of attending from home provides a rare opportunity for participation for some attendees who would otherwise miss out, whilst others enjoy the opportunity to top up their in-person activity with a convenient online session.



Claire with her finished Easter DSEngage craft items.

Kate explains;

As a physiotherapist and parent carer I understand how important good physical and mental health are, how interlinked they are, and the important impact that they have on a person's wellbeing. I also know how important opportunities for participation and inclusion are for people who have Down's syndrome and their families/carers. This of course ties in with the Down's Syndrome Association's commitment to improving the quality and life of people who have Down's syndrome; promoting their right to be included on a full and equal basis with others.

It has been a very positive experience to review the DSAActive Programme which has been a success for many children and adults who have Down's syndrome. It opened doors to sport participation through the creation of Down's syndrome specific teams and competitions at a time when other options for inclusive participation were very limited. However, there have been many changes over the past 15 years, both in the attitudes towards disability within society and in the expectations of families and adults who have Down's syndrome towards participation and inclusion in activities.

Taking part in any activity, whether it's a physical, sporting or other recreational activity, can benefit the physical/mental health and wellbeing of everyone involved. The review confirmed that it was essential that this was true for every part of the programme.

DSEngage participants physical and mental health, and their wellbeing, benefit enormously from attending the sessions, as do mine! A real sense of community has been developed with blossoming friendships too amongst our Disco, Pilates, Workout, and Craft sessions to name just a few. What is great about the sessions is that we can include participants of all abilities as the provider and I can adjust session elements for individuals and families and carers work with us too.

DSEngage is a fantastic and unique provision that we hope will go from strength to strength. We have all experienced the difficulties of getting to in-person activities and for some children and adults those difficulties often have a detrimental effect on the overall benefits of their attendance. DSEngage participation minimises this and the obvious positive impact is clear for all to see on the screen. I feel very privileged to be part of the DSEngage Programme community and to be welcomed on screen into participants homes. If members haven't yet given our sessions a go, as a physio and a parent I would most certainly recommend it for all its benefits, including the tiring effects of a good dance at the 7pm disco.



Zoe showing off her many Brownie Badges and uniform

The consolidation of the previous success of DSAActive and the evolution of the programme will see the **Down's Syndrome Association DSAActive Programme** of support and facilitation go from strength to strength. We will be able to help many more adults and children who have Down's syndrome, their families and the wider community to benefit from improved participation and inclusion. We are all missing out if we are not all able to join in and be included and we hope that no one has to miss out in the future.

The newly evolved Down's Syndrome Association DSAActive Programme:

- We will increase opportunities for people who have Down's syndrome to be included in their community activities through pan disability, learning disability and other recreational and sporting groups.
- We will develop partner organisation networking through online forums and social media to encourage and promote sessions, events and tournaments across England, Wales and Northern Ireland.
- We will provide training and support to partner organisations across all sports and recreational activities.
- We will continue to strengthen DSEngage activities with increased provision for children and adults.



Daniel and James, brothers able to enjoying a sailing session together supported by DSAActive





DSEngage

DSEngage continues to provide lots of fun activities to keep our bodies and minds active.

We have our programme of regular weekly activities:

| DAY | TIME | ACTIVITY |
|-----------|--------------|---------------------------------------|
| Monday | 4pm – 4:45pm | Weekly Workout |
| Tuesday | 4pm or 7pm | 4pm Disco / Evening Disco |
| Wednesday | 6:30pm | Join Mr Motivator at his live workout |
| Thursday | 9:15am | Wake Up and Dance with DanceSyndrome |
| Friday | 4pm – 5pm | Pilates Plus |

Why not keep the copy of the weekly DSEngage timetable on the opposite side of this page handy to remind you of what is on?

Please regularly visit our DSEngage webpage at downs-syndrome.org.uk/DSEngage/ where you will find information about special and seasonal sessions, e.g. art and craft, Christmas/Easter and special event activities.

We hope to see you at a DSEngage session very soon.



DSEngage DSEngage Live Online Session Timetable



Find out more about DSEngage and access all our extra downloadable activities at downs-syndrome.org.uk/dsengage

| Monday | Tuesday | Wednesday | Thursday | Friday |
|---|--|---|---|---|
| Weekly Workout 4.00 - 4.45pm   bit.ly/DSEngageWeeklyWorkout |  4pm Disco 4.00 - 5.00pm  bit.ly/DSEngage4pmDisco OR Evening Disco 7.00 - 8.00pm  bit.ly/DSEngageEveningDisco | Mr Motivator! Live Workout 6.30 - 7.15pm   bit.ly/MrMotivatorDSEngage | Wake Up and Dance with DanceSyndrome 9.15 - 10.00am   bit.ly/DSEngageWakeUpAndDance | Pilates Plus 4.00 - 5.00pm   bit.ly/DSEngagePilatesPlus |

We run two disco sessions - the 4pm Disco and the Evening Disco. The disco sessions happen on alternate Tuesdays. Go to the DSEngage webpage for all the details.

Generous support from some fantastic businesses



2022 got off to a great start with support from Frugi. Found globally in over 550 retailers across 30 countries,

Frugi is the UK's leading ethical and organic children's clothing brand.

The innovative company is based in Cornwall and under the company's Little Clothes BIG Change charity giving project donates 1% of its turnover to charity each year. Frugi chose to support the DSA in 2022 and their very generous grant will support three of our Baby & Pregnancy Support groups.

These online groups provide support for parents of babies up to 18 months of age and expectant parents looking forward to welcoming their new baby. The sessions are free and informal, friendly and inclusive and give the parents a chance to get to know our team, as well as each other. The sessions cover a broad range of topics, like development, communication and benefits, and parents are given many opportunities to ask questions. Our thanks to Frugi for their support for the DSA.

Lara Smrtnik, Head of Marketing at Frugi commented,

'We are so thrilled to be supporting the Down's Syndrome Association and their new parent training courses through Frugi's Little Clothes BIG Change charity programme. These courses provide vital information and support which are imperative to any new or expectant parents. They will help people understand the condition in much greater detail and signpost them to relevant information and resources. Most importantly they will provide a trusted and safe environment for families to share their stories and concerns and to subsequently help each other on their life journey. I know on a personal level how incredibly important these sessions will be for families and Frugi is proud to be able to support them.'



Hilton London Metropole has further extended its support to the DSA with

a generous donation of £5,000 for the DSA's employment programme, WorkFit. Hilton London Metropole has been involved in WorkFit for almost five years and has welcomed and supported people who have Down's syndrome through the programme into a number of work opportunities in the hotel.

Alison Thwaite, WorkFit Project Manager, commented,

'This is a fantastic donation from Hilton Metropole in London.'

'We really appreciate the support of the entire team, and we can't thank them enough for this generous donation which will allow us to continue our valuable work in supporting people who have Down's syndrome to access employment opportunities through the WorkFit programme.'

We welcome support from companies for the DSA's work. For more information on company support and the ways companies can donate to the DSA including being involved in Payroll Giving, a simple and effective way to give to the DSA from your salary, visit downs-syndrome.org.uk/CorporateSupport/



Helpline and Information Centre

0333 1212 300

info@downs-syndrome.org.uk

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

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

Our information resources are freely available on our website.

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

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

Training

training@downs-syndrome.org.uk

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



Get active

www.dsactive.org.uk

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



Employment

www.dsworkfit.org.uk

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



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

LANGDON DOWN
CENTRE

www.langdondowncentre.org.uk

0333 1212 300

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are given outside office hours by
recorded message.

Founder

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Michael Caines MBE
Peter Davison
Dame Judi Dench DBE
Derrick Evans
Perry Fenwick
David Flatman
Shane Geraghty
Sarah Gordy MBE
Sarah Greene
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Damon Hill OBE
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| 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.ds-int.org