

journal



CELEBRATING
50
YEARS
1970 - 2020



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Letter from the Chief Executive



Carol Boys

Welcome to the first issue of *The Journal* for 2020, our 50th anniversary year.

It is wonderful to think that some of the readers of this issue have been members of the Down's Syndrome Association right from its very earliest days. The way we communicate with our members has changed quite a lot over the years, but *The Journal* is still a highly valued way of sharing vital information, important news and inspiring stories.

As it's a significant year for us, there is a thread of historical reflection in this issue's content. There are so many important milestones in our story it is difficult to do them all justice. On page seven, Dr Gerry Coghlan, Consultant Cardiologist and one of our trustees, talks about the scandal that arose around the cardiac services at the Royal Brompton and Harefield in the 1990s and the Down's Syndrome Association's part in the campaign that followed.

Georgia's story gives a parent's perspective of what it was like to be at the heart of the scandal. Thankfully things have changed significantly in the last twenty years, as illustrated in what Tom has written about his daughter Rosie's treatment and care.

I'm very proud of what the Down's Syndrome Association has achieved in the last fifty years and I'm also excited about what the future holds. People with Down's syndrome will continue to be at the heart of all our work and the theme of this year's Awareness Week and World Down Syndrome Day – 'We Decide' – is an important reminder of why this is important.

The United Nations Convention on the Rights of Persons with Disabilities makes the right to meaningful participation in decisions a core human rights principle. Awareness Week gives our community the perfect opportunity to champion this right and tell the world how they can make it a reality for all people with Down's syndrome.

Our 50th anniversary year promises to be full of exciting and important events, new resources, expansion of services ... do make sure you keep up to date with all our news via our website, newsletter (have we got your email address?) and social media.

Information for Contributors

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

We are interested in publishing general articles, news, letters, academic papers, book reviews, arts/exhibition reviews and conference reports, all of which should be specifically related to Down's syndrome.

We include human interest stories on any aspect of life with Down's syndrome. Previous articles by parents have covered all stages of life from birth to adulthood. If you have an interesting story we would like to hear from you.

How to submit

Our document *Information for Contributors* gives full details on submitting an article. If submitting photographs you will also need to complete a DSA photo and film permission form. See www.downs-syndrome.org.uk/about-us/dsa-journal/

Articles submitted for consideration should be sent to: Ian Jones-Healey, DSA Journal Editor ian.jones-healey@downs-syndrome.org.uk

General Notes

We cannot always publish articles as space is limited; articles may be published at a later date if the next issue is full; we reserve the right to edit articles; the Editor may alter articles wherever necessary to ensure they conform to the stylistic and bibliographical conventions of the journal; authors are responsible for all copyright clearance for any third party material/references/images included; if using references please use the Harvard system; photocopying single copies of articles contained in this journal for the purpose of private use is permissible; for multiple copies and reproduction, permission must be sought from the DSA/author(s); copyright is retained by the author(s); if authors use the same material in subsequent publications, acknowledgement should be given to this journal.

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Disclaimer

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 Journal are those of the authors and do not necessarily reflect the official positions or policies of the Editor or Down's Syndrome Association.

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On the Cover: Birthday party.
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News

Shifting Perspectives Podcast

Series two of the Shifting Perspectives Podcast brings more voices from our community to your headphones, tablets, PCs and smart speakers.

Richard Bailey returned to host series two of the Shifting Perspectives podcast in December 2019.

In this series you can hear Richard chatting with an amazing array of guests. Ophir Yaron, a wonderful young woman that Richard has known for many years. Mum, blogger and campaigner Sarah Roberts of 'Don't be Sorry' fame talks about her family, writing and how she went from couch to 5k to London Marathon runner



and #Team21 inspiration. Brothers Alex and Nick Bourne talk about their relationship and their amazing journey to film a special documentary about siblings. Dr Elizabeth Herrievan, who co-produced an influential infographic for health professionals to help them remember certain facts when caring for children with Down's syndrome, talks about being a medical professional and mum to a child with a dual diagnosis of Down's syndrome and ASC (Autism Spectrum Condition). Finally, sportsman, advocate and

Gillingham FC fan Jack Hale talks about his life, achievements and ambitions.

You can listen to all the episodes on our website at www.downs-syndrome.org.uk/ShiftingPerspectivesPodcast/ and they're also available on Apple Podcasts, Google Podcasts, Deezer and Spotify. If you would like to be a guest on our Podcast or know someone who we might like to interview, please contact us via email on DSAPress.Office@downs-syndrome.org.uk

Health Alert! report published

The Health Alert! Campaign report, which includes powerful testimony about people's experience of the healthcare system is now available on our website at www.downs-syndrome.org.uk/HealthAlert/.

We have sent the report to key stakeholders but would ask our members and supporters to raise the issues highlighted in the report with your own MPs.

We are also in the process of developing a specific training

package on Down's syndrome for health care professionals.

We are always looking to hear from our members about their experiences of accessing health care (good or bad), as they help us campaign for change in cases like this.

You can share your stories via email to info@downs-syndrome.org.uk or by calling our Helpline and speaking to one of our Information Officers on 0333 12 12 300.

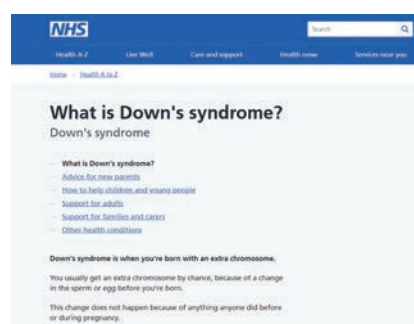


Updated NHS online resource about Down's syndrome

In November 2019, the NHS published updated information about Down's syndrome on their website. This comprehensive online resource is intended as a reference for anyone looking for information about what living with Down's syndrome is like.

We were delighted to have worked with NHS digital on the content of the pages and were very encouraged by the way in which they were keen to involve us and others across the community. They also spoke to

individuals with Down's syndrome and their families.



We feel the new resource captures the 'lived experience' very effectively and will undoubtedly be well used by anyone looking for good quality, up to date and balanced information about Down's syndrome.

We are also pleased to be referenced as an organisation that can provide additional information, advocacy and support at all stages of life.

You can read more about this project later in this issue.

WorkFit® partner XPO win 'Best Employer Practice' Award at the BASE Awards



In October 2019 new statistics revealed that just 5.9% of people with a learning disability are in paid employment. It's a downward trend year-on year, and confirmation that schemes like our WorkFit® programme are vital.

One of WorkFit's most successful partnerships is with XPO Logistics who won the 'Best Employer

Practice' category at the British Association for Supported Employment (BASE) Awards 2019. The company employs seven people with Down's syndrome in their supply chain network across the country in permanent, paid roles.

Watch Sam's story on our YouTube channel (bit.ly/MeetWorkFitCandidateSam)

Right To Be Heard

Last year we submitted evidence to the Department of Health and Social Care consultation on mandatory learning disability training for staff working in these services.

In November, the Government published its response to this consultation in a report called *Right To Be Heard*. We are pleased to see that we are quoted in the report.

In the last quarter of 2020 we

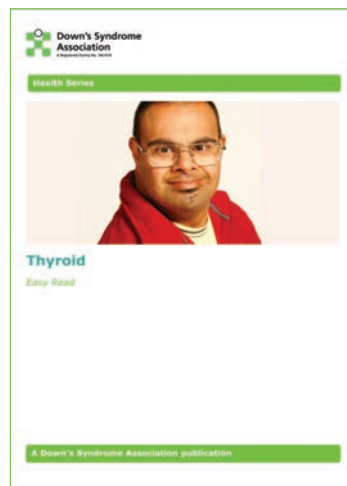
entered into correspondence with the Minister and as the implications of the recent general election become clearer, we will be holding the Government to account in their implementation of the recommendations detailed in the document and will seek to be actively involved in the development and delivery of the training for health and care professionals. This area of our work forms part of our *Health Alert!* Campaign and you can read more about the campaign later on in this issue.



Having a Voice®

The Having A Voice® groups have had a busy six months, helping us create new resources and influencing our campaigns and policy. Late last year they helped us develop a new Easy Read resource on the thyroid which you can find on our website at www.downs-syndrome.org.uk/ThyroidEasyRead/

You can read more about our ambitions for the Having a Voice® project and the way in which it informs the work of the whole charity later on in this issue.



Sara Pickard at the Women of the Year Awards

Advocate, campaigner and member of the DSA, Sara Pickard, joined 400 other inspiring women at the 'Women of the Year' awards lunch last October. Sara and the other guests were all recognised as 'Women of the Year' for their individual achievements. Sara kindly wrote a blog about the lunch and you can read it on our website at www.downs-syndrome.org.uk/SaraWOTYAwards/

House of Commons Education Select Committee publish SEND enquiry report

In October last year the House of Commons Education Select Committee published the findings of its inquiry into special educational needs and disabilities (SEND). They concluded that this generation is being let down by the current system, and that parents are facing a "titanic struggle" to find the right help and support.

We contributed to the Special Education Consortium's submission to the 18-month-inquiry, which received 700 pieces of written evidence. Carol Boys commented:

"This damning report clearly shows that a generation is being let down by the current system. It shows a lack of accountability, a lack of

resources, a lack of joined-up working and a lack of funding. We welcome the fact that the government has commissioned its own review of the system, and hope that these reports are more than just 'reports', and lead to long-term improvements for families, children, and young people with special educational needs."

50 years of the Down's Syndrome Association

By Carol Boys

Rex Brinkworth was a teacher and psychologist whose professional interest in improving outcomes for children with Down's syndrome had been sharpened by the birth of his fourth child, Françoise.

His daughter had Down's syndrome and was quite a poorly baby. While some people suggested Françoise "would 'never be more than a vegetable'" Rex was not going to let the "severe under-expectation, and...conventionally negative medical prognosis" discourage him and his wife from doing their very best for their daughter.

Rex was soon supporting other parents of children with Down's syndrome. The positive and proactive idea that parents could make a difference to their child's well-being was a revolutionary and powerful one.

At that time, people with Down's syndrome were generally referred to as 'mongols'; they were considered to be educationally sub-normal.

Many people with Down's syndrome lived in institutional settings such as long-stay mental hospitals. Parents were often encouraged to leave their children in such institutions and to forget about them. If they did take their children home, they could expect very little support in the community. Most babies and children lived at home with parents rather than in institutions.

By 1969 Rex was in touch with some 130 families. The Down's Babies Association was set up in 1970 to formalise the work that Rex was doing and to give families from all over the country a place to come and receive assessments, information and training.

At this time the Association was working out of a small office in Birmingham. A network of branches slowly extended across the country.

These were made up of families and a few medical, education and social work professionals. Rex produced the first fact sheets for parents containing positive information and activities to help the development of children with Down's syndrome. We still have copies in our archive at the Langdon Down Centre.

This focus on empowerment and information, for people with Down's syndrome and their parents and carers, has been one of the core strands of the organisation's development. Of course, our name has changed – from the Down's Babies Association, to the Down's Children's Association and finally to the Down's Syndrome Association – and as such, our information and advice has expanded accordingly.

Today we offer advice, information, support and resources about any aspect of living with Down's syndrome including prenatal support, benefits, education, service provision, rights, health and well-being, speech, language and communication, complex and adult needs.

Campaigning on critical issues is another important focus for us. From the very start the Association has aimed to change people's expectations and improve understanding of the condition. We have tackled the use of outdated terminology and highlighted inequalities in education, health and social care.

We have challenged the stereotype that people with Down's syndrome can't be fully included in their communities, alongside their peers, holding down jobs, enjoying relationships, getting married and

living a full life. We have funded and supported research into all aspects of Down's syndrome.

Ensuring that people with Down's syndrome are at the centre of our decision-making process is also now a core part of our strategy.

A person with Down's syndrome has been a member of our board of trustees since 1999. The Down 2 Earth group, the first of our Having a Voice® groups, met for the first time in 1997. We are also committed to amplifying the voices of people who have Down's syndrome through all our communication channels.

Throughout the last fifty years our members have been a vital part of our story. They are the powerful engine driving all our work; their feedback helps us define the direction of our work and their membership fees have allowed us to continue to deliver vital support, year on year.

Many of our members and supporters have gone above and beyond with their fundraising efforts. We still rely almost entirely on voluntary donations, big and small, and we are so grateful for every one of them. Our Affiliated Groups are also a vital part of our network.

So, what about the next 50 years? The DSA will continue to be the driving force for fundamental change in our society that it has been since 1970. Although we've come a very long way, our work will not be complete until people with Down's syndrome are fully included into society and no longer the victims of discrimination and prejudice.

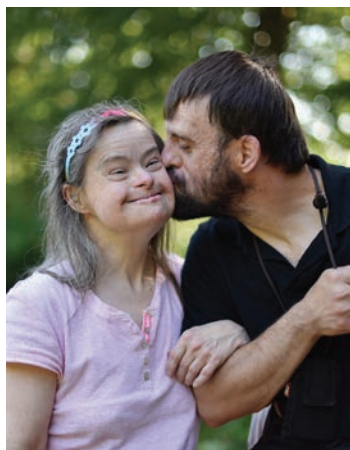
Memories and Stories project

We are thrilled to have been awarded a grant from the National Lottery Heritage Fund to create a very special celebration to mark our 50th anniversary.

Combining photos and oral histories the project, which will be launching in April, will transform the Langdon Down Centre.

We will be shining a light on people who have Down's syndrome aged fifty and older. Their stories and portraits will be the heart of a new exhibition that will be on display throughout the building.

A team including some of the leading lights of British photography have been pulled together by Richard Bailey (who previously curated the Shifting Perspectives exhibitions and is our head judge for the annual My Perspective competition) to capture the portraits.



Photograph by Marcel Jancovic / Shutterstock.com

A milestone in cardiac care

Dr Gerry Coghlan, Consultant Cardiologist,
Down's Syndrome Association trustee

Heart defects are found in around 1 in 100 babies, but in about 1/2 of those born with Down's syndrome, and is usually severe enough to require an operation. Every child with Down's syndrome should have an echocardiogram shortly after birth ideally within the first month, earlier if there are any breathing problems or if suspicions have been raised by ultrasounds done during pregnancy.

In the 1990's it was clear from parent's complaints that in some national centers of excellence people with Down's syndrome were not valued. Parents were being encouraged to 'consider whether putting their child through surgery was best, given their disability' leaving many children to deteriorate and die, usually in their early twenties, despite the availability of highly successful surgery. Georgia's story is a typical example of the callous approach being taken. Georgia's parents, unlike others, were not cowed into simply accepting the advice given.

An independent inquiry into paediatric cardiac surgery services at the Royal Brompton and Harefield was started in 1999 in response to concerns raised by a whistleblower, evidence provided by the Down's Heart Group and the Down's Syndrome Association. Direct evidence from parents and evidence of medical discrimination collected by the Down's Syndrome Association (in the report He'll Never Join the Army) were pivotal to one of the major findings of this report – that discrimination was a problem among some senior doctors at the Royal Brompton Hospital.

In response to this inquiry, Carol Boys as Chief Executive and myself as a trustee of the a Down's Syndrome Association, were invited to join a panel to implement the Trust's response to the inquiry's findings and to ensure that the culture of the organization was changed. The panel was chaired by the Chief executive of the Royal Brompton

and met regularly over two years. The trust engaged positively with the process and appropriate training and oversight at every level of the organization was put in place to ensure that discrimination because of disability is no longer tolerated within the institution. We were invited back to see for ourselves the results of the changes implemented and can now confidently recommend the Royal Brompton as a welcoming place for people with Down's syndrome, where first class treatment is available to all on an equal basis.

Rosie's story shows that this best practice has spread within the UK in the last twenty years. Unfortunately, care is not yet consistent across the country; many people born with Down's syndrome are still not getting echocardiography early enough or at all. Until that changes, people will continue to progress unnecessarily to untreatable heart disease leading to disabling breathlessness and premature death in the UK.

The Down's Syndrome Association is currently supporting research to discover the extent of the problem around failure to offer early echocardiography. We are also working with other Down's syndrome organisations and medical experts from around the world to develop surveillance and treatment health guidelines for all children and adults with Down's syndrome. Our aim is to achieve World Health Organisation recognition for these Guidelines so that governments cannot ignore them. This work continues alongside our Health Alert campaign, addressing concerns on wider health care issues, which you can read about later in this issue.

Georgia's story

by Sarah Leggat

Georgia Rachel Leggat arrived, somewhat earlier than expected, on a December day in 1992. Colin and I were told the morning after her birth that she had Down's syndrome.



Over the next few weeks we began to accept that diagnosis and found out more about what a child with Down's syndrome might bring to our lives and the challenges that would come along too. We began to believe we could cope.

The wonderful paediatric team at Maidstone Hospital supported us every step of the way. Early on it was explained that some 40% of babies with Down's syndrome have some sort of heart defect and that an appointment would be made at the next Outreach Clinic of The Royal Brompton Hospital, held at Maidstone Hospital, to check her heart.

The appointment date duly came and along we went. The doctor scanned Georgia thoroughly and then spoke with his team. Then he gently told us that Georgia had an Atrial Ventricular Septal Defect which, without medical or surgical intervention, would limit her life. In fact he said a lot more than that but after the diagnosis we didn't hear the rest.

Georgia's Consultant Paediatrician

at Maidstone Hospital took us aside later and explained everything very clearly and gave us the time we needed to take it all on board. To be told your baby is not the one you expected is hard, but to then be told that she had a major heart defect that might curtail her life is even harder, just as we were beginning to truly love her. The shareholders of tissue and vodka manufacturers were doing well at this point!

We were then given an appointment at The Royal Brompton Hospital in London for Georgia to have more detailed scans and tests. The consultant in charge that day looked at the results of everything that had been carried out and told us that Georgia could have the operation. He then explained that Georgia could go down the medical route but the drugs involved would only be effective until about her mid-teens, when surgery would not be possible at all. He pointed out the obvious risks of surgery but then went on to talk about the investment the hospital would be making in our daughter to buy her extra years and the time she would

have to spend in the hospital and the cost. He clearly mentioned a figure of £12,000 and that this should be taken into consideration, bearing in mind Georgia was not 'normal'.

Colin and I made it very clear that we had already decided that if surgery was possible Georgia had the right to the chance of as long a life as possible and that, fortunately, was our firm decision.

When we left that appointment, we stopped in the corridor and almost said in unison to each other 'Did he say what I think he said?' The doctor had, indeed, clearly implied that our daughter was not worth the time and cost of surgery because she had Down's syndrome. He talked about Georgia as her diagnosis as a baby with Down's syndrome, not as our beautiful child.

Time went on and Georgia's condition deteriorated. She spent a lot of time in Maidstone Hospital, frequently having to be intubated (put on a ventilator) and had a spell in the Paediatric Intensive Care Unit at The Royal Brompton Hospital. Surgery was being held off as long as possible to give Georgia a chance to grow as strong as possible.

However in April 1993 she deteriorated again and was readmitted to Maidstone Hospital. She became so unwell that she and I experienced a Blue Light ambulance transfer back up to The Royal Brompton Hospital, where they stabilised her condition. A date was booked for surgery.

During the first week of May 1993 we handed our little girl over to

the surgical team and spent one of the longest days of our lives, not knowing whether she would make it through the challenging day. This was before mobile phones were common, so we were without any contact until we returned to the hospital. Parents who have been through similar experiences will know just how hard it is. We met up with my parents and our other daughter Lizzy. It was an extremely odd day.

We returned to the hospital later in the afternoon and were assured that Georgia had come through her ordeal. The surgeon came and explained what he had done in mending the AVSD and that one of the valves had not been working properly so he had mended it as well. While he was talking to us, I became fixated on his enormous hands. They had spent the day working on our daughter's heart, the size of a small plum!

We were also told that they had pushed the limit on the time usually accepted for a baby to be on a heart bypass machine, but the push had given the surgical team the time required to fully mend Georgia.

There were a number of setbacks and Georgia remained in Intensive Care much longer than expected but eventually she was weaned off the ventilator and could breathe unaided. Once she moved across to the regular paediatric ward we began to calm down. Our daughter had turned pink in colour, which we were not used to, and then we would worry ourselves because her chest was moving so gently as she breathed. We were not used to seeing her breathing quietly!

She was sent back to Maidstone Hospital for a few days and finally back home. Barring the attitude of one individual the NHS did her proud and we remain grateful to all the hospital staff who not only looked after Georgia, but also supported us in so many ways. Our other towers of strength during this time were our parents, who kept Lizzy's routine going while we were in London

so much and friends who brought meals and were just there for us.

The whole experience was, and remains, tarnished by the attitude of the cardiac consultant. As our lives settled down and Georgia went from strength to strength, I became involved with the Down's Syndrome Association, becoming a Trustee more than 20 years ago. The organisation had been hearing about issues surrounding two Doctors at The Royal Brompton Hospital and contacted all parents whose children had been treated there, which included ourselves.

When a panel was convened to look at the alleged cases of discrimination, I was one of the parents interviewed in 1999. By this time Georgia was about 8 years old and happy at school. To go over that time of our lives again was extremely difficult.

The Inquiry and the Down's Syndrome Association provided excellent support to the parents and I was able to relive our experience, although it was very difficult and emotional. All Colin and I wanted was that no other parents of babies with Down's syndrome should ever have the worth of their baby questioned.

Georgia is now almost 27 years old and is an amazing young woman. She started her education in the village school and then attended two super Special Schools, finishing her education at a Residential Camphill College. She now lives with 7 other young people in Supported Living just 10 minutes from us.

The residents are a wonderful group, all with different challenges in their lives. They are all busy with various activities during the week but do lots of things together socially. They almost always get together on Sundays and prepare a roast dinner, they go to the gym, drama groups, go to the cinema, shopping, the pub and go on holiday. She has a very full and active life and LOVES to party! She likes to come home if we are having friends or family round but not when it is just us and boring ordinary time!

We know our place!

While Colin and I do not dwell on the past we still find the fact that the value of our child's life was questioned very difficult. It has left an indelible mark on us.



Rosie

By Tom Bachofner

My beautiful daughter Rosie was born in March 2011 with Down's syndrome and a Complete Atrioventricular Septal Defect (AVSD).

We knew Rosie had a potential problem with her heart at around 24 weeks thanks to the various scans and tests that were undertaken. We were sent to Manchester Childrens Hospital where the scanning equipment is more advanced and they confirmed that she had a hole in her heart. They couldn't say for sure the extent as she was still so small and developing, in some cases, we were told, these initial heart defects can even heal themselves before birth. We had regular scans from here on and the final scan prior to Rosie's birth (whilst not conclusive) led us to believe the hole had decreased in size and may not even require surgery. However, when Rosie born we discovered this was not the case and the hole was still present. At just six months old, in September 2011, Rosie had to endure over seven hours of open-heart surgery which as you can imagine, was a very traumatic time for the whole family.

It's important to know that the risk of death at the time of Rosie's operation was as low as 3–5%, however, nothing quite prepares you for the moment you meet the surgeon pre-theatre and they tell you there is a chance your baby may not survive. Whilst the stats were reassuringly low, it didn't make the signing of the consent forms any easier. This was the moment all the waiting accelerated to reality for me personally.

Only one of us was allowed to take Rosie in for the anaesthetic and we decided it would be me. I was absolutely determined to be strong for both my girls, 'keep it together



Tom' I kept telling myself as I felt it was vital that Rosie saw me smiling when she went to sleep.

Her eyes gazed into mine, feeling safe in daddy's arms. The bond I had with Rosie reached a whole new level at this moment and for a split second, I had an urge to take her back home – after all she looked happy with no visible signs of heart problems, maybe they got it wrong and really she's fine?...

I reluctantly placed her on the bed and gave her my biggest smile whilst the tears streamed. She looked at me as if to say, "I'm fine Daddy, pull yourself together and let me get this over with". Then she closed her eyes...

Five and a half hours eventually passed and we went up to the ward she was admitted from to sit in the waiting room, thinking any minute now... A further hour and a half passed, totalling seven hours in surgery. I remember the last hour, every second felt like a minute. We didn't know if it was taking longer

because of complications, we just had to sit tight.

When the call eventually came we raced up to see her at the Intensive Care Unit (ICU). I had never been in an ICU before and really had no idea what to expect – I remember feeling like I'd stepped onto the set of some US hospital drama. But, laying peacefully amongst all the mayhem was Rosie. I physically can't write down how I felt when I saw her, I've tried but it's just a bit too distressing. After the initial urgency, the surgeons and all but one nurse left her bedside then things settled down. We both sat and stared at Rosie in awe and I remember feeling an enormous sense of pride in my daughter, so tiny, having come through the initial operation. It goes without saying how much I respect the NHS, but I really can't stress enough just how impressed I was with the work ethic of every nurse on the ICU and I will always be eternally grateful. Rosie was on the ICU for a total of three days. In most cases, it's one to two days, however during the second night

we received a call to say they'd had to operate immediately to insert another drain as they'd discovered she had a 'pneumothorax' – a collapsed lung due to air being trapped between the lung and chest wall which prevents the lung from inflating fully. This was a little set back in terms of recovery time, but we were assured it was very routine and no cause for major concern, although given our worn out state it didn't feel like that at the time. So, on the fourth day post-surgery, Rosie was finally given the green light to be moved from ICU and onto the ward. Whilst she wasn't completely out of the woods, it was a huge step in the right direction and the feeling of relief and excitement was unforgettable.

One thing we weren't prepared for was how long we'd have to wait

until we could hold her in our arms again. Five days in total... but that first cuddle, post-surgery, was a moment I don't think either Karen or I will ever forget. Rosie finally came out of hospital seven days later. To have her home was a great relief as we could now start to plan ahead as a family, concentrating on raising Rosie without the anxiety of major surgery looming.

The need for surgery significantly delayed Rosie's physical development in her first year. Now eight years on she is living life to the full, doing all the things you might expect from an eight year old. She really enjoys singing, dancing, engaging in role-play (as either her teacher or a make-up artist) and possesses the skillset needed to keep her older brothers wrapped around her finger!



Each year we celebrate the anniversary of her surgery as 'Rosie's Happy Heart Day' and reflect on how thankful we are to the entire NHS team at Alder Hey, who were not only extremely professional but compassionate too and they will always be remembered by our family as Rosie's heart heroes.

Awareness Week 2020

16-22 March 2020

"We decide"

All people with Down's syndrome should have full participation in decision making about matters relating to or affecting their lives.

The right to meaningful participation is a core human rights principle supported by the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Sadly, negative attitudes, low expectations, discrimination and exclusion, still mean that people with Down's syndrome are being left behind and do not have the opportunities to participate fully in decision making about matters relating to or affecting their lives at all levels.

At the root of this discrimination and exclusion is a **lack of understanding** about the challenges people with Down's syndrome have to face in their everyday lives **and a failure to support them** with the opportunities and tools needed so that they can participate fully in society.

For Awareness Week this year we will be:

- Challenging society's attitudes, expectations and understanding of what it means to have Down's syndrome.
- Amplifying the voices of people with Down's syndrome telling us what they think about the importance of more effective and meaningful participation.
- Celebrating our Having a Voice® project and the vital contribution its participants make to steering and guiding our work.
- Promoting our FREE resources and tools that can be used to support anybody with Down's syndrome to participate meaningfully in all areas of life.

What you can do to help

- We would love to hear **YOUR** stories.
- Share, share, share via your own social media profiles.
- Wear your **#LotsOfSocks** with pride throughout the week as well as on World Down Syndrome Day.
- Hold an event at your school, workplace, place of worship or social club.
- Tell people who want to know more to give our Helpline a call.

My Perspective 2020 open for entries

We're very much looking forward to seeing all the entries for this year's My Perspective competition ... the closing date is 31 March so there's not much time left to submit a photograph.

This year's competition is a special one as we will be marking the 10th anniversary of My Perspective. We have seen some amazing photographs over the years ... and we're thrilled that photographers from around the world continue to share their work as part of this unique competition.

In the same way as last year, we're asking photographers to put their images into categories when they enter: Landscape; Portrait; Abstract; Animals and My Life. There will be two winners – one chosen by our panel of judges and one chosen by a public vote. We will, of course, be also awarding the Stephen Thomas Award to an international photographer.

Find out more about the competition and how to enter at www.downs-syndrome.org.uk/MyPerspective



2010: Sun by Rory Davies



2011: Half-boat and Weed, Portsoy by David Cormack



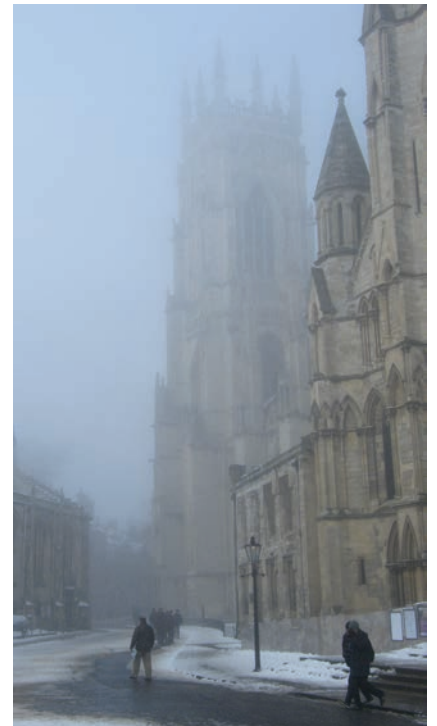
2012: Brighton Beach Huts by Victoria Campos-Davis



2013: Trees by Daniel Tomes



2014: Moraine Lake by Stephen Thomas



2015: Misty Minster by David Kenward



2016: Reflection by Emily Buck



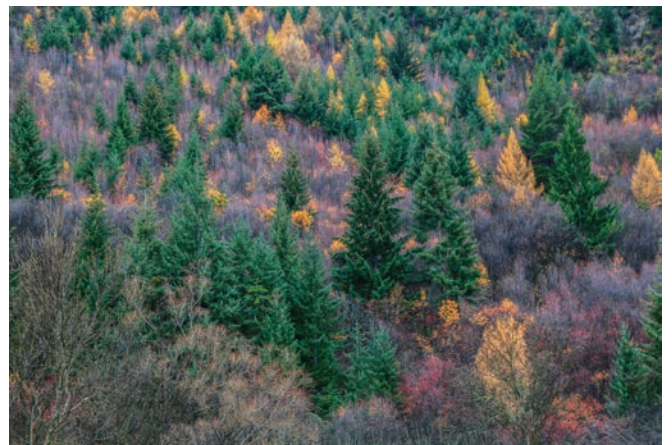
2017: Red Kite by Oliver Hellowell



2018: Seven Sisters by Emily Buck



2019: Judge's Choice – Blue Tit in the Snow by Oliver Hellowell and People's Choice – Autumn Leaves in Arrowtown by Carlos Biggemann



Over a century of healthy change

*“Success can only be obtained by keeping the patient in the highest possible health.”¹
If you had to guess, when would you say that quote was written?*

You would be forgiven for thinking it was written in the last 20 years, given the exponential growth in the number of research papers looking at diet, health and physical activity in people with Down's syndrome since the year 2000.

It was actually written in 1882 by Dr John Langdon Down, in reference to how he intended to support people with Down's syndrome and learning disabilities to reach their highest potential. He understood the importance of health and wellbeing for those under his care. When they were healthy, they were able to work, to communicate better, to enjoy leisure activities and to play sport. He encouraged all his patients to dance, to try gymnastics, and to get involved in riding, cycling, cricket, tennis and football. However, this was not a philosophy shared by many at the time and it meant that the possible sporting achievements of people with Down's syndrome would not be fully realised until more recent times.

People with Down's syndrome are more likely to have additional health conditions which can be potential barriers to participating in sport and physical activity. Unfortunately, these health conditions meant that many held the view that people with Down's syndrome would never be able to compete in sport.

Although this wasn't the view of Dr Langdon Down, it would take another 80 years before another professional shared his view. Eunice Kennedy Shriver understood the power of sport to bring people from different walks of life together and she couldn't understand why there was no provision for those with learning disabilities. In 1962 she invited a group of people with learning disabilities to attend a summer camp in her back garden. She ran sporting events for them and

saw the potential of the athletes. Six years later, she ran the very first Special Olympics competition which attracted athletes with learning disabilities from all over the world.

Eunice faced a lot of criticism for running the event. Many experts informed her that it would be harmful for people with Down's syndrome to compete and that people with Down's syndrome had 'negative buoyancy' and would not be able to swim. Thankfully, she ignored them, and society slowly started to see the sporting potential of people with Down's syndrome.

Not only was there a perception that people with Down's syndrome could not be physically active and play sport, but there was a negative stereotype regarding their weight and size. For many people with Down's syndrome, managing their weight can be a challenge. Research has shown that over 70% of people with Down's syndrome are overweight or obese and that people with Down's syndrome tend to eat a diet higher in fatty foods and low in fruit and vegetables².

It wasn't until the launch of the Down Syndrome Medical Interest Group in 1996, that academics and researchers started to investigate the health conditions associated with Down's syndrome and the possible negative effects on health and wellbeing. For example, thyroid disorders (at all ages thyroid disorders occur more frequently in people with Down's syndrome than in the general population³) have been linked to an increased chance of obesity⁴, and hypotonia and hypermobility can make physical activity challenging. Research has also looked at the difficulties people with Down's syndrome might have with swallowing and tongue control, both of which can limit the amount of foods that can be consumed.



It is not until very recently, that researchers and organisations have started to change their thinking around diet and nutrition for people with Down's syndrome. The focus has finally shifted from what people with Down's syndrome **can't eat**, to what people with Down's syndrome **can eat** and how their diet can be optimised. This can be seen in the Health Swap project run by the DSAActive team, which developed a nutrition app specifically for people with Down's syndrome. More information can be found on our website www.dsactive.org.uk.

This same shift in view, from what people with Down's syndrome can't do to what they can, has also occurred in sport and physical activity in the last 20 years. The Down's Syndrome Association's DSAActive programme was launched back in 2006. It was a response to research showing that 70% of people with Down's syndrome were overweight or obese², and that parents were reporting a severe lack of opportunities for their child to get involved in sport and physical activity. It was also being widely reported that very few people with Down's syndrome were able to participate in mixed disability sporting sessions and needed a different entry point in to sport and physical activity. Since the programme was launched over 1,000 people with Down's syndrome are now regularly participating in sport and physical activity, thanks to sessions supported by the DSAActive team.

The DSAActive team have also been a part of the significant shift in the wider sporting landscape to provide more opportunities for people with disabilities to compete on a national and international level. There are now more opportunities than ever before for athletes with Down's syndrome to compete on a national and international level, including events run by DSAActive, National Governing Bodies, the Sports Union for Athletes with Down Syndrome (SU-DS), INAS (now known as Virtus: World Intellectual Impairment Sport), Special Olympics and most notably since 2012 the Paralympic Games.

The more competitions and events there are the more we have seen just what people with Down's syndrome can achieve. For example, who will forget Simon Beresford

becoming the first man with Down's syndrome to run the London Marathon in 2007?

As it's the Down's Syndrome Association's 50th year, we have all had the chance to take a step back and reflect on the changes to the lives of people with Down's syndrome that we as an organisation have supported. There is no doubt that the sporting provision and nutritional advice for people with Down's syndrome has changed beyond recognition, though we still have a long way to go. We will continue to strive to ensure there are more opportunities for people with Down's syndrome to be active and healthy, and perhaps we can dare to dream of someone with Down's syndrome winning gold for their country in the Paralympics one day.

References

1. Tales of Normansfield; The Langdon Down Legacy. Andy Merriman.
2. Phillips, A. C., & Holland, A. J. (2010). An Investigation of Physical Activity in Individuals with Down's Syndrome.
3. Down Syndrome Medical Interest Group – Thyroid <https://www.dsmig.org.uk/information-resources/guidance-for-essential-medical-surveillance/>
4. Biondi, B (2010). Thyroid and Obesity: An Intriguing Relationship, The Journal of Clinical Endocrinology & Metabolism, 95 (8,1), 3614-3617.

World Down Syndrome Congress (WDSC) Dubai World Trade Center, Dubai, UAE 15-17 November 2020



The Emirates Down Syndrome Association is hosting the 14th World Down Syndrome Congress (WDSC) in November 2020. The event brings together people with Down syndrome, their families and advocates, experts, specialists and researchers in the field of Down syndrome.

- The congress will include recent significant developments, quality research in key areas of global relevance to people with Down syndrome.
- Topics of interest will include health, education, employment, sports, recreation and leisure. Focus will be on human rights based issues (in line with the United Nations Convention on the Rights of People with Disability (UNCPRD)) such as

ensuring an adequate standard of living, social protection, legal recognition, social and cultural inclusion and the right to live an independent life.

- The WDSC, the largest global congress for people with Down syndrome, is a family based event and an opportunity to share and hear their inspiring success stories, the challenges facing people with Down syndrome, and to gain knowledge and experience about self- advocacy, empowerment and social inclusion.

The previous WDSC held in Glasgow in 2018, attracted 1,200 delegates from all over the world. What they reported they liked best was the opportunity to network, the quality of the speakers, hearing people with Down syndrome speak about

their lives and feeling like [they were] part of a community. Vanessa Dos Santos, President of Down Syndrome International says of WDSC 2020:

'This will be the first time the WDSC has been in the Middle East and the event promises to inform, inspire and influence everyone who attends for years into the future. It has been really encouraging to see the high level of interest in WDSC 2020 from all over the world'.

For more information and to register for the event please go to the WDSC 2020 website: <https://wdsc2020.org.ae/>.

Please note early bird registration deadline is 15 June 2020.

Having a Voice®

We are delighted with Down Syndrome International's concept for World Down Syndrome Day 2020 – We Decide – which is also the theme of this year's Awareness Week.



One of the DSA's strategic aims is to involve adults who have Down's syndrome in our work, creating opportunities for people to be the voice of the organisation and continuing to ensure that people are involved at all levels.

To help to meet these objectives we support a growing self-advocacy project, Having a Voice®, through which people with Down's syndrome can express their opinions and share their experiences, influence their communities and guide our work.

Having a Voice® members belong to a network of peers with whom they can discuss the issues that matter to them and which directly influence our work, including contributing to local and national policy. Having a Voice® meetings also encourage friendships and enable people with Down's syndrome to express themselves. The groups welcome and include members who have little or no spoken language and/or dual diagnoses with autism and other conditions. Currently, we support three groups with 50 members who meet regularly in Devon, London and North Wales. For example, members co-produce projects and resources, guide future services

and research, and contribute as stakeholders through representation to our Board of Trustees.

Activities and outcomes

Example 1

At a recent meeting members told us what they would like people to know about having Down's syndrome. This open session led to contributions about inclusion in society with themes on Down's syndrome being a lifelong condition, health, communication, travelling, education, work, interests, money, language terminology, friends and family.

Some of the quotes below show that there is a great deal more still to do to make life better for people who have Down's syndrome:

"You have it since you were born"

"A part of me"

"Hole in my heart"

"When I was young, blocked ears, deaf qualities in my ears, affected me when I was little"

"Like to be rich, to have more money for CDs"

"Treat people with Down's syndrome equally. Help them"

"They (people who have Down's syndrome) have people they care about in the world. It is important to care about people"

"Friends, people I care about"

"Some people use Makaton and sign language"

"I can't help it, body reaction"

"It is rude when people look at me and say you've got Down's syndrome. Why would you say that? Not very nice to talk to me like that, not to say things"

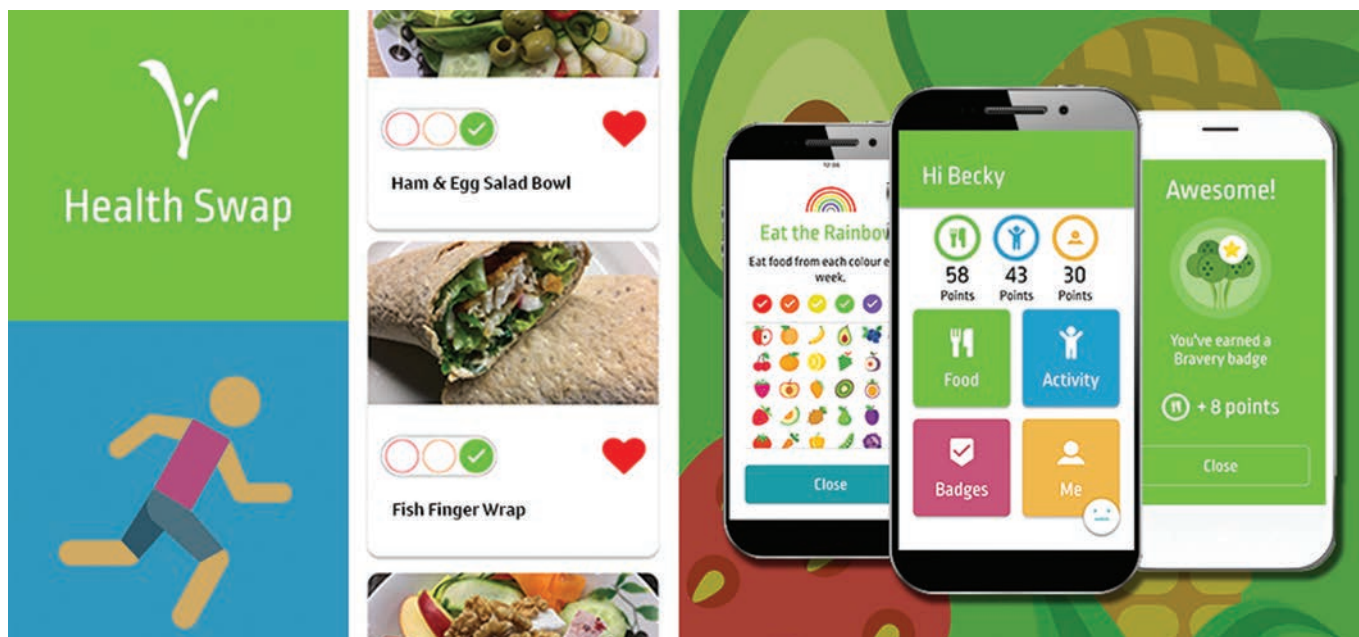
"On the bus, look at driver; say I will tell my parents. Look, I know I have Down's syndrome, but not talk about it in this environment. We are normal people in England. Not want that word now. Not this environment. Not want to talk about it. Do not talk about it in front of me" (referring to people on the bus talking about them)

"Everyone must be included"

"Hobbies and interests, writing, drawing"

"Sports, football, rugby, Grand Prix, dancing, singing, people"

"Looking for a football team but I have neck..." (neck instability)



*"Sometimes I get bullied by it.
Not fair. Two people are equal"*

"Crossing road – be careful"

"Go to school, college, the same"

"Work"

*"Need to speak up. Relax and
calm, talk"*

Example 2

At a different meeting, members considered the DSA's sports and well-being project, DSAActive. They talked about activities they would like to participate in that are not currently part of the project, investigated healthy meal options on the DSAActive 'Health Swap App' and consulted on picture images and designs to create new healthy lifestyle resources.

Members said the app "Gives goals", "Helps you with what to achieve", "Keeps you going", "Makes you do more". Some members already enjoy skiing, squash, dancing, swimming, tennis, badminton, Zumba, cross training, bowling, walking, yoga, gym, weightlifting, football, cycling, rowing, boxing, golf, horse riding, surfing and sailing and said they would like to try archery, rock climbing, kite surfing, paragliding, zipwire and kayaking.

At the same meeting, members also developed a new, accessible

resource about the thyroid to accompany a Thyroid Guideline produced by the Down Syndrome Medical Interest Group (DSMIG). This Easy Read resource covers:

- What is the thyroid and what does it do?
- Sometimes your thyroid gland might not work properly
- How will you feel if you have an underactive thyroid?
- How will you feel if you have an overactive thyroid?
- How does your doctor check your thyroid is working properly?
- How will the medication make me feel?

<https://www.downs-syndrome.org.uk/download-package/thyroid/>

Example 3

Members worked with staff and volunteers to co-produce a range of resources to promote emotional wellbeing in children and adults. This new information for parent carers, as well as resources for people with Down's syndrome, will be highlighted in the next issue of the Journal.

Example 4

Members of one of our groups have invited local councillors to

their meeting to find out how local decisions are made and how they can influence decisions. We will tell you what they thought about their meeting and what they found out in the next issue of the Journal.

More from Having a Voice members

"It is a good group. It is more strong and powerful to talk about my own life and stuff you want to do. I am looking forward to being able to Skype with other groups like in London. People should be involved with the DSA because they are trying to help people with Down's syndrome."

"It is interesting and I like it. I like seeing new people and some of my friends in my past. I like dealing with money." A member speaking after a session on money management.

"I like Having a Voice, I think it is a good thing. I had never seen so many people with Down's syndrome at the same time."

"I believe in the power of free speech, and sometimes I need help to have this. So do a lot of other people with Down's syndrome. We need respect."

"You can't say it everywhere but you can say it here. It's the right place!"

WorkFit® – celebrating success

As we celebrate 50 years of the Down's Syndrome Association, we have an opportunity to reflect on several significant milestones achieved by the charity in delivering its objective to provide the conditions for people who have Down's syndrome to live full and rewarding lives.

The WorkFit® programme was launched in 2011 in response to an extensive review of employment opportunities for our members in 2008. Since the subsequent publication of our report "The Invisible Workforce" there have been some considerable developments. These include a significant increase in the number of candidates registered with WorkFit®, based on increased awareness of the skills and abilities of our candidates through successful placements.

In conjunction with that, the number of employers supporting those candidates has increased to almost 500 and we have seen a remarkable expansion in the range of industry sectors that we are working with.

70% of the employment opportunities that we develop are in the private sector and we have expanded into fields such as Arts & Heritage, Banking, Construction, Leisure, Science, Sport and Warehouse/Logistics. This range shows that we are committed to increasing the interests, skills, and experiences of our candidates beyond the more customary roles that our candidates may have previously been encouraged to pursue in Catering, Hospitality and Retail sectors. In the public sector we have developed significant partnerships with the

Police and with Fire and Rescue services and with a number of government departments including the Ministry of Justice, Department for Education, the NHS, and DEFRA/ Environment Agency.

WorkFit® has always worked on a "presumption of employment" believing that everyone can work in the right job and with the right level of support. The WorkFit® model provides sustainable employment opportunities with 92% of candidates recruited to permanent paid jobs still in those roles 2 years later (excluding redundancy).

We now have over 1,000 candidates registered with WorkFit®, all at different stages on their career pathway. Many are in permanent paid work with others opting for shorter-term employment opportunities to suit their needs and circumstances. As well as offering permanent paid work, candidates can choose to do work experience, work taster sessions, volunteering or supported internships/apprenticeships. Some of our candidates are still waiting to be assessed and the WorkFit® team of eight Employment Development Officers covers England and Wales, working tirelessly to develop a range of opportunities to meet their needs and ambitions.



WorkFit® has won several awards over the past seven years with our programme being acknowledged by a range of organisations in both the supported employment and disability sectors. This reflects the hard work and dedication of the DSA in supporting the career ambitions of our members and providing 50 years of support to ensure that our members are afforded every opportunity to succeed.

To see our candidates in their jobs and hear from them and their employers, our YouTube channel can be found at: <http://bit.ly/workfityoutube>

WorkFit® supports people with Down's syndrome to access meaningful work opportunities that can benefit the rest of their lives. For more information about WorkFit® 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: www.dsworkfit.org.uk



The NHS and Down's syndrome

Over the last year, we have been very closely involved with an important project working with NHS Digital in completely rewriting the information they give about Down's syndrome.

Increasingly the general public, professionals working in the field and families who have a particular interest in knowing more about Down's syndrome, turn to online resources. We are very aware of the importance of the language used and wanted to ensure that the information given on the NHS website is up-to-date and accurate. The focus of this information has now been vastly improved, with many members who have seen the relevant sections commenting that they like the tone and emphasis these new pages of information give.

You can see the resources by visiting www.nhs.uk/conditions/downs-syndrome

In continuing our focus on improving sources of information, we were very pleased to participate in an important piece of work led by The University of Leeds. This saw the production of guidance for sonographers supporting pregnant women and their partners in accessing ultrasound scans and will advise on the correct use of language. It will help sonographers to understand the information and support needs of women at this important time in their pregnancy. It also signposts sonographers to the support available from the DSA and encourages them to promote this to the women and couples they are supporting. This new resource compliments the work we have been doing within maternity services across the country, under our (free) Tell it Right® accredited training.

Since our last Journal we have trained a further 350 midwifery



staff in locations including: Worthing; Frimley Park Hospital, Surrey; Lancashire; Swansea and at an event hosted by The Royal College of Midwives in Cardiff.

We have recently produced postcards that summarize our Helpline and the support and information we are able to provide women and couples during a pregnancy (including support around antenatal screening) and after a new baby with Down's syndrome is born and have distributed these to every maternity unit in the country.

Training and Support

Training Services

Our training services have continued to expand with the addition of a new full-day course aimed at supporting families of adults (or those approaching transition to adulthood). We were very grateful to the Stepping Stones Support Group in Hampshire who hosted us to deliver one of these new sessions in the early autumn. We have also recently provided a series of training days hosted by support groups in Manchester and Swindon and also held a family weekend event for parents of younger children with Down's syndrome in Manchester.

We are looking forward to an education day hosted by the Liverpool Down's Syndrome Support Group later this summer.

Complex Needs

We were pleased to have secured funding for our team to provide a series of regional complex needs

days, focused on the families of children and adults with Down's syndrome who have a dual diagnosis of autistic spectrum condition. These workshop style events were held in Cardiff, Middlesex, Liverpool and Hull and have proved to be very helpful to those who attended. One parent commented

"Very relevant and informative – it was wonderful to spend time with people who understand, finding my tribe" and another said "Great opportunities for sharing between attendees, which really helped. Very supportive guidance given by presenters – excellent quality of information on both dual diagnosis and mindfulness".

Don't forget our closed Facebook group for families of children and adults with Down's syndrome and complex needs. For further information on how you can request a bespoke training day

or online training session on one of these topics please email training@downs-syndrome.org.uk. A brief list of the themes is below:

- Tell it Right® (free for all maternity settings)
- Early Development birth to 4
- Primary education
- Secondary education
- Social development and behaviour
- Puberty and sexuality
- Supporting adults
- Ageing well
- Complex needs support

In addition to travelling the country delivering the training sessions outlined above, we continue to facilitate our scheduled training programme at The Langdon Down Centre. A full list of these sessions is listed on our website www.downs-syndrome.org.uk/for-professionals/training.

We are developing our online services this year and will shortly be making announcements about new opportunities for you to access online consultations and advice.

Older Family Carers

We are currently doing much to increase the support available for older family carers. Julian Hallett, Services Development Manager, was delighted to be invited to sit on a panel at a recent event in Hampshire, hosted by Baroness Jolly, which launched a report by Professor Rachel Forrester-Jones of Bath University detailing the experiences of older family-carers in that area.

We are also working with the Growing Older with a Learning Disability group in facilitating a conference for service providers and professionals supporting older people with Down's syndrome to be held in London in the summer. This will event will feature presentations from lead researchers in the field, including Dr Andre Strydom from Kings College, London. More information on this will be available from Julian.hallett@downs-syndrome.org.uk

We have just launched a new Closed Facebook group for family-carers of older people with Down's syndrome and dementia. You can ask to join this group by emailing Julian.hallett@downs-syndrome.org.uk or looking for it on our main Facebook page. www.facebook.com/groups/DementiaDSA

Helpline

A reminder about our Helpline **0333 1212 300** open Monday to Friday 10am to 4pm.

In addition to providing information, support and a listening ear, we can facilitate specialist advice from one of our advisors:

Speech, Language and Communication (Gwen Toner)
Psychologist (Geraldine White)
Welfare Benefits (Helen Wild)
Social Care Advocacy (Chris Watson)

Research on the transition from school to adult service: Transition Voices – Navigating Change

Paula Jacobs

Transitions from school to adult services have been identified as an area of concern across the UK.

Policies and resources available in local areas play crucial roles and shape the process to a large extent.

As part of my PhD I decided to explore the transition journeys of three young people with severe learning disabilities and limited verbal communication to focus particularly on how young people are involved in decisions made.

When I began my research I wanted to find answers to the following questions:

How are young people with limited verbal communication involved in the transition process?

And how do families and professionals work together?

To find answers to my questions I followed three young people in Scotland on their transition from school to adult services over three months. I spent time with young people at their school and/or new adult service and I interviewed those that were involved in making decisions in each case, which included: parents, social workers, teachers, adult service staff, health professionals and local authority managers.

Themes reflected the complexity of how to support young people on their journey into adulthood. The transition posed questions about the involvement of young people in the decision-making

process, and how to understand the concept of adulthood when young people continue to depend on others across the course of their lives. Very strikingly, families seemed to be alone in their worries for the long-term future.

The following is a summary of my findings. A detailed presentation and discussion of the study has been published by the journal Disability & Society (<https://doi.org/10.1080/09687599.2019.1669435>).

1. Practical and organisational processes

My study suggests that the transition needs to be differentiated into two processes:

- (1) Supporting the young person with the actual move and
- (2) Funding and placement decisions.

Parents and professionals in my study described the practical move as very positive in all three cases, with good communication between the schools, the new adult service and families. People thought carefully about activities the young people would enjoy and how to help them understand the move. The practical transition appeared to be centered on the needs of the young person but this was less apparent in decisions made about funding or the timing of the move.

Parents voiced concerns about fixed maximum amounts of budgets and everyone reflected on paucity of local adult services.

National policies, promoting person-centeredness and individualisation, seemed to describe 'the ideal scenario' and local authority managers and social workers talked about the difficulties to put those ideals into practice while being faced with a decrease in budgets and a shift in local authorities towards providing less services. Many adult services were described as running at capacity and there were differences in fees. This could mean that families were faced with a cut in respite to finance a five-day adult service. It was clear that there were tensions between conceptualising choice as what families ideally liked and choices being inherently linked to what was available.

2. Involvement of young people and families

Participants felt that young people had very little involvement in the transition process. Everyone seemed to connect the concept of choice with the ability to verbalise wishes and views, which was not possible for the young people in my study. However, other parts of the interviews illustrated that young people were involved and able to communicate their preferences because they expressed how they felt in different environments and communicated their needs through their behaviour. This was taken into account when identifying adult services, making plans about the move and when deciding on programs and activities.

Families and young people seemed to have very little involvement in 'wider' decision-making such as deciding when transition planning should start and being involved in the kind of services available to them. Those decisions seemed to be shaped largely by existing service delivery and available budgets. In all cases parents would have liked to start planning for the transition earlier.

3. Relationships between families and professionals

Problems did not seem to relate to relationships between families and professionals but to limitations within the political system. There was a sense that everyone was trying their best within a climate of funding cuts and paucity of services.

Almost all participants, from parents to social workers to local authority management, felt that their possibilities were limited by decisions that were made 'higher' and which they were unable to influence.

4. Transitions: The need for a life course understanding

Parents were the only ones who explicitly talked about the transition in terms of the long-term future, planning for a time when they would not be able to look after or advocate on behalf of their children any longer. Families were clearly asking for a whole life-course understanding but felt that professionals often viewed the transition as a single move from one service to another.

My study found positive examples of how families and young people can be involved within practical decision-making. However, there continues to be a need to facilitate involvement of families within organisational processes, despite a call for families to be involved in the planning of service-delivery within policies and international agreements.

Although interviews highlighted challenges and complexities in how to involve young people with little verbal communication and severe learning disabilities, there was evidence that if those close to young people are attuned and receptive to their communication they are able to advocate on their behalf, as young people were communicating their preferences and likes through their behaviour. Yet, this also highlights the vulnerability of young people who do not have closely involved families as advocates.

Professionals need to have a good understanding of young people's everyday life experiences, their preferences, abilities and needs to involve them in the process.

To facilitate an involvement that is based on detailed knowledge requires time and close collaboration between different people involved in the person's life. Others have recommended that transition planning should be available from age 14 and should continue to at least age 25. Yet, to truly reflect a life-course understanding everyone involved needs to be aware that the needs and preferences of young people will change throughout adulthood. The move to adult services should not be seen as 'mission complete', as families will continue to need support from professionals to plan for future changes throughout their child's adult life. High staff turnover in both social care and social work often contribute to a feeling of uncertainty and inconsistency, which makes it difficult for parents to trust services and for young people to be involved and heard.

If you would like to find out more about my study please listen to the story of James:

To highlight the perspectives of different people involved in my study I developed an audio play that tells the story of a young man called James*. Interview extracts from parents and professionals across the three cases are used to tell his story. At times minor changes needed to be made to fit James's story but most extracts are direct quotes from my interviews.

The audio play can be accessed via soundcloud: <https://soundcloud.com/user-839751792/transition-voices-navigating-change-2>

Paula Jacobs is originally from Germany and moved to Scotland in 2007. In Scotland she worked in different learning disability services, both for children and adults, for 9 years before starting her PhD in September 2016.

Parents' experience of having a child with the dual-diagnosis of Down's syndrome and Autism Spectrum Condition: A Narrative Analysis

Dr Katherine Lambert, Clinical Psychologist

What is the dual-diagnosis of Down's Syndrome and Autism Spectrum Disorder?

It was previously considered that Down's syndrome (DS) and Autism Spectrum Disorders (ASD) could rarely co-occur. However, recent research indicates variable but relatively high rates of ASD in children with DS (Warner et al., 2014).

A review of the literature exploring the possible distinguishable features of individuals with the dual-diagnosis of DS and ASD (DS-ASD) supports the concept that individuals with DS-ASD present with features that are distinct from what one might expect from a child with DS and without ASD (Hepburn et al., 2008; Cater et al., 2007). In comparison to children with ASD-only, children with DS-ASD tend to:

- Have a similar profile of communication, stereotypical behaviours and difficulties coping with changes in routine (Moss et al., 2012).
- Be less affected by social difficulties, impairment in imaginative play and problems with eye-gaze (Warner et al., 2017).
- Demonstrate more preoccupation with body movements and compulsions and rituals.
- Have strengths in adaptive functioning and relating to others (Hepburn et al., 2008; Carter et al., 2007).
- Present with higher levels of hyperactivity. (Moss et al., 2012).

Furthermore, children with DS-ASD are more likely to have severe to profound levels of learning disability in comparison to children who have

DS without ASD (Buckley, 2005). With this in mind some have queried whether the diagnosis of autism is an accurate conclusion in individuals with severe cognitive deficits or whether such difficulties result in diagnostic overshadowing and delayed or miss-diagnosed ASD (Starr et al., 2005; DiGuseppi et al., 2010; Molley et al., 2009).

Diagnostic classification and the applicability of screening measures are also raised as a concern (DiGuseppi et al., 2010; Buckley, 2005; Lowental et al., 2010). However, according to evidence, when cognitive ability and reliability and validity of screening measures and diagnostic clarification are controlled for, a differential profile and diagnostic criteria remain applicable (Molley et al., 2009; Ji et al., 2011; Moss et al., 2012).

Background and context of the current study

While research has focused on exploring the behavioural profiles of those with DS-ASD, and despite wider evidence outlining the potential emotional and practical implications of having a child with a developmental disability, parents' experiences of the dual-diagnosis largely have been overlooked. Instead, generalisations and speculations are gained from parents' experience of having a child with a disability or who have a child with either DS or ASD, but not both.

Current study

This exploratory study sought to explore how parents of children with Down's syndrome experience and make sense of their child's additional ASD diagnosis.

In order to gather accounts that were rich in detail and meaning, in-depth, face-to-face interviews were undertaken with six parents of children with the confirmed dual-diagnosis (DS-ASD), recruited from the Down's Syndrome Association (DSA). Participants were invited to tell their stories about having a child with the dual-diagnosis of DS-ASD.

The interviews were conversational in style and nature. Participants were encouraged to describe situations and circumstances they had found especially significant or important related to their child's dual-diagnosis and to explore the impact and meaning the dual-diagnosis has in their everyday lives and role as a parent.

Given the study's particular interest in parents' experiences across time and different circumstances and to explore how parents have come to understand and find meaning and coherence, a structured narrative analysis was used. Both the content of the participants' accounts and how participants told their stories, including the tone and manner in which they described their experiences were analysed (Crossley, 2000; McAdams, 1993).

The Findings

The findings suggest participants have difficulty making sense of their child's diagnoses of Down's syndrome and ASD and what this means for their identity, sense of belonging and where best to seek support.

All the participants described a distinction between a 'Down's syndrome' identity or group and that of an 'ASD' identity. Drawing

upon this distinction and a sense of not belonging or fitting in, terms such as 'camp' and 'tribe' were used by the participants. Some participants spoke about having 'one foot in both camps', others stated that they do not 'fit in either' or consider themselves on the periphery of an already minority group of parents of children with a disability.

To navigate this and seek a sense of belonging and meaning, parents talked about ways they have come to understand, respond and engage with their child's dual-diagnosis. For some their child's ASD diagnosis has a more significant impact on their daily, family life compared to that of the Down's syndrome. Others reflected that the complexity of the dual-diagnosis largely precludes the separation of the two conditions, describing DS-ASD as a 'cocktail' where the two conditions are mixed together. A level of adjustment and acceptance was implied by some participants in their accounts of their child's behaviour and family circumstances becoming the 'new norm'.

All the participants spoke about ways in which they respond to having a child with DS-ASD. Although warmth and affection in tone and content was evident across the accounts, a sense of increased responsibility was expressed by the participants.

"... you are a carer, you're an advocate, you're a protector, which I am not saying you're not with another child but ... everything he needs explaining to the outside world and we're the ones to do it".

For some participants their role as a parent has developed and expanded. Most of the participants spoke about a 'need' to seek knowledge and understanding of the dual-diagnosis, to 'get it right' and be sufficiently organised and prepared in order to manage circumstances and situations effectively for their child and family.

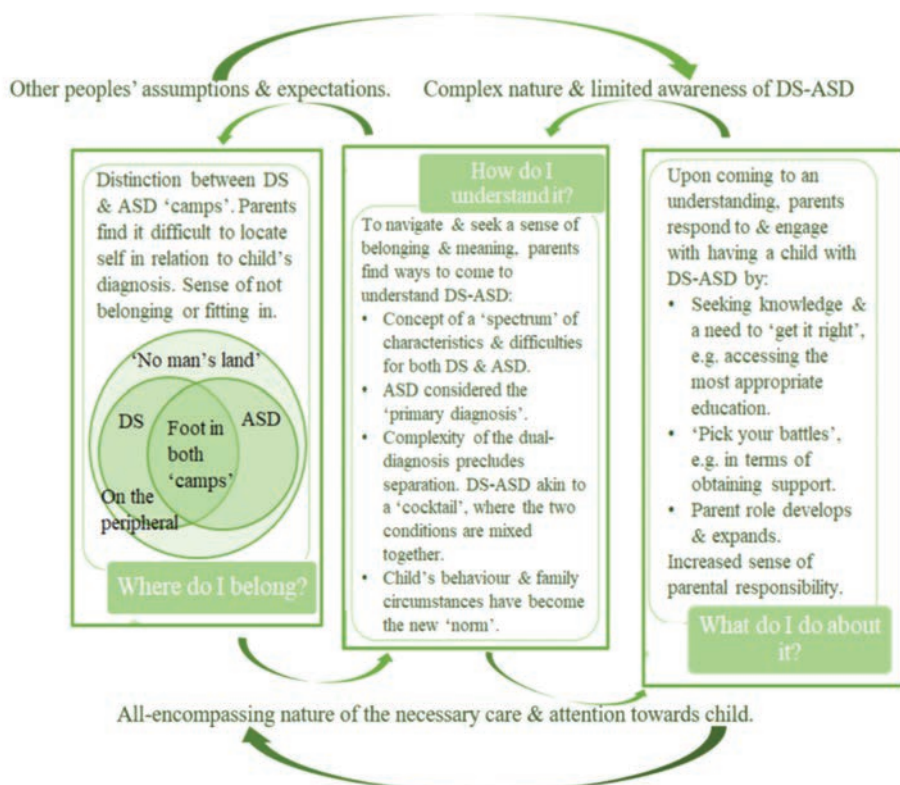
Accessing the most appropriate support, particularly regarding choosing the 'right' and applicable educational provision was an especially important issue raised by most of the participants. Furthermore, some expressed a need to 'pick your battles' as part of this process. However, for a number of participants, by having the opportunity, for example, to provide recommendations for learning and communication strategies for their child's school, this provided a role and sense of identity. Some of the parents reflected on how they have perhaps come to be perceived by others as an 'ambassador' or 'expert' given their input and commitment to supporting their child. While the intended outcome of such actions by parents was principally to assist and support their child, it nonetheless had an impact on parental role and identity.

The diagram is a tentative visual representation of the findings in order to highlight the extent to which the participants' experiences and sense-making process is complex, continuous and non-linear.

In addition to considering the content of the participants' accounts, part of the analysis involved the exploration of the manner in which the participants' told their stories. For example, participants used imagery and metaphors to help describe their experiences and to convey meaning, especially regarding particularly challenging circumstances.

In some of the participants' accounts the tone was optimistic, aided by the use of humour. While this may have perhaps concealed the extent to which the participants spoke about challenges, others were more explicit in their description of the difficulties. There were fewer incidents of laughter and metaphors and imagery such as 'conflict' and 'battle' were used.

The findings gathered in this study support previous research which



outlines the importance of the search for and integration of meaning in the process of acceptance and adjustment for parents of children with a disability and the extent to which this provides an opportunity for personal growth and a shift in parents' perspectives.

Conclusion, Implications & Future Research

The findings demonstrate the challenging nature and complexity of what it means to parent a child with DS-ASD and the meaning that comes from parents' developing an understanding of their child.

While there are some small pockets of support for parents, these tend to focus on the informal sharing of practical ideas, experiences and suggestions. However, this small-scale exploratory study provides some evidence to indicate that it may be necessary to consider the provision of support specifically for parents of children with DS-ASD.

Furthermore, from the accounts gathered from the participants and given that having a child with the dual-diagnosis involves numerous changes and transitions, parents are likely to benefit from having the opportunity to share their stories and reflect on what the complexities and contradictions, as well as some of the positive and optimistic experiences, mean to them.

A DS-ASD specific, therapeutically-based parent support group would be one such way a space for mutual awareness and understanding could be facilitated for parents and carers.

A support group could also facilitate research opportunities and thus address a key limitation of the study regarding whether it captures different parental perspectives. For example, by meeting and engaging with more parents and carers, this would aid access to a wider section of participants and a broader range of experiences and perspectives.

References

- Buckley, S. (2005). Autism and Down Syndrome. *Down Syndrome News and Update*, 4(4), 114-120. doi: 10.3104/updates.341.
- Carter, J.C., Capone, G.T., Gray, R.M., Cox, C.S., & Kaufmann, W.E. (2007). Autism-Spectrum Disorders in Down Syndrome: Further delineation and distinction from other behavioural abnormalities. *American Journal of Medical Genetics, Part B: Neuropsychiatric Genetics*, 144(1), 87-94. doi: 10.1002/ajmg.b.30407.
- Crossley, M.L. (2000). *Introducing Narrative Psychology: Self, Trauma, and the Construction of Meaning*. UK: Open University Press.
- DiGuseppi, C., Hepburn, S., Davis, J.M., Fidler, D.J., Hartway, S., Lee, N.R., Miller, L., Rutterenber, M., & Robinson, C. (2010). Screening for Autism Spectrum Disorders in Children with Down Syndrome: Population Prevalence and Screening Test Characteristics. *Journal of Developmental Paediatrics*, 31(3), 181-191. doi: 10.1097/DBP.0b013e3181d5aa6d.
- Hepburn, S., Philofsky, A., Fidler, D.J., & Rogers, S. (2008). Autism Symptoms in Toddlers with Down Syndrome: A Descriptive Study. *Journal of Applied Research in Intellectual Disorders*, 21(1), 48-57. doi: 10.1111/j.1468-3148.2007.00368.x.
- Ji, N.Y., Capone, G.T., & Kaufmann, W.E. (2011). Autism Spectrum Disorder in Down Syndrome: Cluster Analysis of Aberrant Behaviour Checklist Data Supports Diagnosis. *Journal of Intellectual Disability Research*, 55(11), 1064-1077. doi: 10.1111/j.1365-2788.2011.01465.x.
- Lowenthal, R., Mercadante, M.T., Filho, J.F.B., Pilotto, R.F., & De Paula, C.S. (2010). Autism Spectrum Disorder in Down Syndrome: Definitional of the Cut-off Point for the Autism Screening Questionnaire Screening Instrument. *Journal of Developmental and Behavioural Paediatrics*, 31(8), 684. doi: 10.1097/DBP.0b013e3181f4a067.
- McAdams, D.P. (1993). *Stories we Live By*. New York: William Morrow and Company.
- Molley, C.A., Murray, D.S., Kinsman, A., Castillo, H., Mitchell, T., Hickey, F.J., & Patterson, B. (2009). Differences in the Clinical Presentation of Trisomy 21 With and Without Autism. *Journal of Intellectual Disability Research*, 53(2), 143-151. doi: 10.1111/j.1395-2788.01138.x.
- Moss, J., Richards, C., Nelson, L., & Oliver, C. (2012). Prevalence of Autism Spectrum Disorder Symptomatology and Related Behavioural Characteristics in Individuals with Down Syndrome. *Autism*, 17(4), 390-404. doi: 10.1177/1362361312442790.
- Starr, E.M., Berument, S.K., Tomlins, M., Papanikolaou, & Rutter, M. (2005). Brief Report: Autism in Individuals with Down Syndrome. *Journal of Autism and Developmental Disorders*, 35(5), 665-673. doi: 10.1007/s10803-005-0010-0.
- Warner, G., Howlin, P., Salomone, E., Moss, J., & Charman, T. (2017). Profiles of Children with Down Syndrome who Meet Screening Criteria for Autism Spectrum Disorder (ASD): A Comparison with Children Diagnosed with ASD Attending Specialist Schools. *Journal of Intellectual Disability Research*, 61(1), 75-82. Doi: 10.1111/jir.12344.
- Warner, G., Moss, J., Smith, P., & Howlin, P. (2014). Autism Characteristics and Behavioural Disturbances in ~500 Children with Down's syndrome in England and Wales. *Autism Research*, 7(4), 433-441. doi: 10.1002/aur.1371.

Preventing infection in children with Down's syndrome

Dr Liz Marder, Counsultant Paediatrician, Community and Neurodisability, and Information lead / Web Editor, Down Syndrome Medical Interest Group, UK and Ireland.

Why should we worry about infections in children with Down's syndrome?

Children with Down's syndrome are particularly susceptible to some infections when compared to other children. Infections they are most likely to get include infections of the upper airways such as ear infections or sinusitis, of the lower airways including chest infections, bronchiolitis and pneumonia, and skin and periodontal (affecting the gums) infections.

Not only are children with Down's syndrome more likely to get these infections but when they do so there is a greater chance of them becoming seriously unwell. They are more likely than the general population to be admitted to hospital with an infection, more likely to need intensive care and to have longer hospital stays. Although the vast majority of children will respond well to treatment for their infections, the mortality rate for infection in children with Down's syndrome is higher than in the general population.

Why are infections more of a problem in children with Down's syndrome?

Children with Down's syndrome are more susceptible to infections because of a number of different factors. This includes differences in their immune system, differences in body structures and in relation to some particular illnesses that more commonly occur in people with Down's syndrome.

Immune system factors

The immune system, which is the body's mechanism for fighting infection, works less effectively

in many individuals with Down's syndrome. There may be lower levels of the white blood cells which fight infection and the body may produce lower levels of antibodies against some infections. Despite this, most of the time the child with Down's syndrome will be able to fight infections effectively, and build up immunity to infections they have been exposed to naturally and through immunisations.

Differences in body structure

Children with Down's syndrome have differences in the structure of various parts of their body. The upper airways may be quite narrow, and the mid face structures less well developed, predisposing them to upper airway infections such as ear infection, sinusitis and croup. Differences in the formation of the lower airways and lungs make respiratory infections such as bronchiolitis and pneumonia more likely.

About half of all children with Down's syndrome will have differences in the structure of the heart (congenital heart disease). Often this will affect blood flow to the lungs making respiratory infection more likely. Many of the children who have congenital heart disease will require surgery to correct the problem, in early childhood. This does however bring with it a risk of infection around the time of surgery.

Hypotonia or low muscle tone commonly occurs in children with Down's syndrome and can also make infection more likely. Difficulties with controlling the muscles of the mouth and throat may make feeding and swallowing uncoordinated, with the risk of aspiration or fluids spilling into

the airways. This makes respiratory infections more likely. Similarly gastroesophageal reflux commonly occurs in young children with Down's syndrome and regurgitated gastric fluid can also spill over into the lungs, leading to respiratory infection.

Other illnesses associated with Down's syndrome

There are a number of other medical conditions that are more likely to occur in people with Down's syndrome and can also be associated with increasing the susceptibility to infection. These include diabetes and blood disorders.

Any short-term illness or longer term health condition that can lead to poor nutrition can also make people particularly vulnerable to infection. Nutritional difficulties can be associated with many of the problems described above.

What can we do about it?

The good news is that there are a lot of things that parents, carers and health professionals can do to help prevent infection in children with Down's syndrome.

Good hygiene

Good general standards of hygiene in the home and care settings, as well as personal hygiene can help prevent skin infection in particular. Good dental hygiene including tooth brushing will help prevent gum disease.

Avoiding contact with infections

We are all unknowingly in contact with infections in our day to day lives and this helps us build up our immunity. However, it is worth avoiding contact with people who you know to be infectious.

Nutrition

A healthy balanced diet, and appropriate weight gain are important in preventing infection. This can sometimes be a challenge in children with other health problems and feeding difficulties.

Iron and vitamin D deficiency are both common in young children with Down's syndrome. Checking for this, and giving supplements where necessary is appropriate.

Immunisation

It is strongly recommended that children with Down's syndrome have all the usual childhood immunisations. Additional vaccines should also be considered. This may include:

- annual influenza vaccine (this is routinely given as nasal spray for children in the UK from the age of 2, but may also be given as an injection from 6 months of age);
- Pneumovax II protects against some types of bacterial pneumonia (the usual UK childhood vaccine schedule does include vaccines against the same group of bacteria but Pneumovax offers protection against more strains of this bacteria);

- monthly injections against RSV (respiratory syncytial virus) one of the viruses causing bronchiolitis may also be considered for those waiting for surgery for certain heart problems, or those requiring long term oxygen therapy.

Most children will make an adequate response to their immunisations, but the response rate is not 100% and it may be worth checking if they have responded through a blood test following their course of immunisations. Some vaccines can be repeated if there is evidence of an inadequate response.

Investigating and treating problems that may predispose to infection

All children get infections from time to time. However, for those who have frequent or severe infections it is worth considering whether there may be an underlying cause. Some of the tests that may be considered include:

- Blood tests to check the immune system is working properly;
- Blood tests to check nutritional status (e.g. Iron and vitamin D);
- Sleep studies to look for upper airway obstruction in sleep;

- Ph/impedance studies to check for gastroesophageal reflux;
- Urine test for diabetes.

If any condition that may make infection more likely is found it should then be promptly treated.

Prophylactic antibiotics

For children who are particularly vulnerable to respiratory infections your doctor may suggest they go on prophylactic antibiotics. This is usually at a lower dose than would be used for treating an infection, and continued long term e.g. right throughout the winter months or for several years, while the child remains vulnerable

Early recognition and prompt treatment of potential infections

It is important that people caring for people with Down's syndrome, including health professionals, as well as their parents and carers are aware of the vulnerability of children with Down's syndrome to infection, recognise the signs of possible infection early, and treat promptly – see linked article below on recognising illness in children with Down's syndrome.

Recognition of Serious Illness in Children with Down's syndrome

Dr Liz Herrievan, Consultant in Paediatric Emergency Medicine
(and mother to Amy, 13, who happens to have Down's syndrome)

We know that children with Down's syndrome are more likely than other children to become unwell. When they do, they tend to get more ill more quickly. We also know that the quicker a serious illness is recognised, the quicker it can be treated and the better the outcome. However, we also know that it can be really difficult, for doctors as well as families, to know whether an illness is serious or not, particularly

in children with Down's syndrome.

One of the reasons for this is that children (whether they have an extra chromosome or not) can be very good at compensating for an illness and can actually appear to be ok until their defences are overwhelmed. Children's hearts are great at adapting to an illness, beating faster to ensure an adequate circulation. That circulation is also

excellent, diverting blood to areas that need it.

Children's lungs work a little harder to ensure enough oxygen is getting in and their kidneys hold onto fluid to prevent dehydration. All this means that a child can look ok, even though an illness is taking hold. Adults are nowhere near as good at this. This compensation gives us some clues though...a

faster heart rate, cool hands and feet, fewer wet nappies or faster breathing, for example.

When the body gets overwhelmed and is unable to compensate, then the child can become drowsy or lethargic, maybe very pale or ashen and may have weak breathing.

Often people worry about a temperature. A temperature can be a sign of infection, but the height of the temperature doesn't really tell us anything. Any temperature of 38°C or more in a baby under 3 months or a temperature above 39°C in a baby between 3 and 6 months is worrying, but otherwise the height of the temperature is less important than how well the child is coping with it. A child with a high temperature who is running around is better than a child without a temperature who is lethargic with cold hands and feet and difficulty breathing, for example.

Some children with Down's syndrome seem less able to control their temperature than others. These children may become cold when they're unwell, rather than hot, or their temperature may not change at all.

Some children with Down's syndrome have more trouble than others with controlling their circulation and can become very mottled or "corn beefy". Some may be prone to developing rashes at the drop of a hat and some may always seem to have a cough or snotty nose, even when they are otherwise quite well.

These things all make it more difficult for parents and health professionals to know if a child with Down's syndrome is seriously ill or not, so there is work going on to look at things known as "Soft Signs". These are things that you don't need any medical training to recognise but which might give a clue as to whether someone is ill.

Different children will have different

soft signs which are relevant to them. Things like not wanting their favourite food, not wanting to watch their favourite television programme, looking more pale than usual or being more agitated than usual may all be significant. You know your child best and this is where soft signs are important.

Another area in which families and carers can help is with supporting the doctor or nurse during any examination. The usual tricks that the doctor might use to help him or her examine a child might not work if your child has differences in understanding or sensory processing, for example, and many doctors are taught very little about learning disabilities during their training (plans are in place for this to change!). It can be really useful if you can help with distracting your child, for example, or just as helpful if you let the doctor know no amount of distraction will help! Again, you know your child best and you know what works and what doesn't for them!

There is a lot of work going on to spread awareness amongst health professionals about serious illness in children and adults with Down's syndrome and other forms of learning disability.

One area which is being highlighted is diagnostic overshadowing. This is where someone has a pre-existing diagnosis (such as Down's syndrome) and the health professional puts any new symptoms down to this diagnosis rather than looking for another cause. For example, they may assume your child is quiet and floppy because they have Down's syndrome, rather than looking for an infection.

The only ways around diagnostic overshadowing are for health professionals to realise they are at risk of it and for families and carers to point out when behaviours are normal for their child and when they are not.

Sepsis is an issue which worries a lot

of people – families and professionals alike. There is no one symptom or sign that tells us someone has sepsis and there is no one test that gives us the answer either. Sepsis is when the body over-reacts to an infection and it's very difficult to diagnose.

Sepsis can also develop during the course of an illness, so it might be that a child is seen by a doctor who diagnoses a viral infection, for example, but later the child develops sepsis. It doesn't necessarily mean the doctor missed it, it maybe it wasn't there initially. There are some "Red Flags" which can help us to diagnose sepsis, but none of them are perfect. These are:

- Not responding normally
- Not waking up properly or being unable to stay awake
- Not interested in doing anything
- Weak, high-pitched or continuous cry
- Grunting or bleating noises with every breath
- Very fast breathing or difficulty breathing
- Pauses in breathing
- Very pale, ashen or blue skin (or mottled, if this is unusual for your child)
- A rash that doesn't fade when pressed

Sometimes people are worried about calling an ambulance or may think they can get to the hospital more quickly on their own. Don't forget though, an ambulance doesn't just provide transport but can bring expert help, along with oxygen and other drugs and equipment.

Things which absolutely need an ambulance, for example, are:

- Severe difficulty breathing;
- Not breathing;
- A fit or convulsion;
- Being unconscious.

Don't forget to trust your gut instinct. This has nothing to do with your bowels, and everything to do with how well you know your child and recognising something isn't right, even if you don't know what that something is.

Down's syndrome infographic:
https://docs.wixstatic.com/ugd/bbd630_66493959a5824ca5a59514207a38d8d3.pdf

Stop and Watch (NHS Cumbria) – one version of Soft Signs:
<http://www.northcumbriaccg.nhs.uk/about-us/safeguarding/stop-and-watch.aspx>



DSMIG was established in 1996 by 17 paediatricians. It has grown to become a network of approximately 160 healthcare professionals from the UK, Republic of Ireland and further afield. Our aim is to help promote equitable provision of medical care for all people with Down syndrome in the UK and Ireland by disseminating a wide range of information about the medical aspects of the syndrome and promoting interest in its specialist management. We are a registered charity and are the only organisation to provide this type of medical-specific service in the UK. We receive no statutory funding.



www.dsmig.org.uk

You can listen to Liz talking about her family and professional life in her episode of our Shifting Perspectives podcast. Go to www.downs-syndrome.org.uk/ShiftingPerspectivesPodcast/ to listen.

Best practice for administering medicines to people with Down's syndrome

Danielle Adams, Specialist Mental Health Pharmacist and PhD Candidate, Centre for Educational Development, Appraisal and Research, University of Warwick. Barry Jubraj, Associate Director, Medicines Use & Safety and Visiting Senior Lecturer, University College London School of Pharmacy

Medication is a key intervention in healthcare in order to maintain health and wellbeing, prevent illness, manage symptoms or to cure disease.

The term 'medicines optimisation' is an approach that seeks to help patients and the public to get the best out of their medicines in the safest way possible. The NHS has published a long term plan (<https://www.england.nhs.uk/personalisedcare/upc/>), describing the key concepts of universal personalised care, in which individuals have choices and control over their care, based on 'what matters' to them and involving shared decision making. These are important because they are about putting the patient

first, including empowering them to make choices around medicines. Healthcare professionals need to think about the patient's experience and what is important to them when initiating a new medicine or reviewing existing medicines.

A key area of medicines optimisation is ensuring that the person or the person providing support is aware of how to administer oral medicines and what action to take if there are challenges in this area. This article outlines some of the risks of

inappropriate methods of medicines administration, for example crushing tablets; how to ask about alternative formulations and routes of administration; and where to seek further information.

Medicines are available in a variety of oral formulations including tablets, capsules and liquids as well as creams, injections, sprays, drops, inhalers amongst others. The majority of medicines are taken by mouth in the form of tablets or capsules with the expectation that

these medicines will be swallowed. However, some people experience difficulty in swallowing tablets or capsules (this is known as dysphagia) and pharmacists are well-placed to advise on what to do, for example whether an alternative is available.

Sometimes it is the size of the actual capsule or tablet that poses a challenge rather than dysphagia itself. In this case a switch to a similar medicine that is available in a smaller capsule/tablet size or taking several lower strength tablets instead of one large one may provide a solution. Some medicines are available in liquid form or soluble tablets. However, they may not be palatable to some people and the medicine may be refused. Liquid preparations are often aimed at children who typically require smaller doses. Therefore, an adult may need to take a large volume of liquid, which may not be possible.

Where a difficulty in swallowing has been established it may be tempting to crush the tablet or empty the contents of the capsule and mix with food. For some medicines this can be an appropriate course of action. However for others this may reduce the effectiveness of a medicine and for some may even increase the risk of adverse effects. For example, enteric coated tablets have a coating on them to allow them to be broken down and absorbed in the alkaline conditions of the small intestine rather than the acid conditions of the stomach. The purpose of this is either to protect the stomach from medicines that could be irritant or to protect the medicine from being destroyed by stomach acid. Crushing enteric coated preparations may destroy this coating and therefore can result in the medicine not being fully absorbed, reducing its effectiveness. For some medicines, the lack of an enteric coating can cause gastric intestinal irritation.

Another type of oral medication that should not be crushed is a 'modified release' formulation. These are typically taken once or twice a day to release the medicine over a 24 hour period to maintain

constant blood levels. This is particularly useful where a medicine would otherwise need to be taken multiple times a day which can affect something known as 'medication adherence', which means whether patients take their medication as prescribed. Multiple daily doses are more likely to be forgotten and doses may not be spaced evenly throughout the day to optimise constant blood levels. Crushing these types of preparation can damage the modified release mechanism and consequently the preparation becomes an immediate release formulation. This could mean that a dose designed to be released over 24 hours may be released over a few hours leading to excessive plasma levels at the beginning of the 24 hour period but then possibly inadequate levels later on in the day, causing adverse effects and less control of symptoms of the condition being treated.

Another important area to reflect on is the impact of mixing the crushed tablet or a liquid medicine with food. We need to be mindful that medicines may adversely affect the taste and texture of food leading to a person refusing to eat.

Pharmacists are ideally placed to advise on whether it is appropriate to crush a particular medicine preparation and the availability of suitable alternatives. Community pharmacies, an accessible healthcare resource on the high street, often open long hours can provide appointments booked in advance to discuss medication. Some GP practices now employ pharmacists who can be accessed via an appointment system.

An area of frequent misunderstanding is the difference between mixing medicines in food to aid administration and the disguising / hiding of medicines in food to facilitate administering of medicines.

If medicines are disguised in food in order to administer then this is known as 'covert administration'. This decision can only be taken if there is a lack of mental capacity

to consent to taking medication and therefore it is appropriate to be acting in the person's best interests. The legal issues about capacity, consent and best interests apply to everyone and is not related to where a person lives or to who provides the support.

However the decision to administer covertly should not be taken alone by one person and must include a discussion with the medical team, the completing of paperwork and ideally input from a pharmacist as to the optimal way to administer the prescribed medicines, including suitability of crushing medicines, and alternative formulations. A person with capacity to consent has the legal right to refuse to take a medicine.

Finally we need to examine the reasons why medicines are being refused. Reasons for refusal can be varied including the tablets/capsules being too large to swallow, too many tablets to swallow, the taste of the medicines and adverse effects.

Underpinning this whole process should be regular medication monitoring and review of all the medicines prescribed, giving consideration as to whether medicines prescribed still remain appropriate and need to be continued on a long term basis. Failure of all stakeholders to engage in conversations around the administration of medicines can lead to medicines being taken erratically, inappropriately or suddenly stopped without the knowledge of the healthcare team.

The person prescribed the medicines, the care team and the relatives are all in a position to prompt for medication review, contributing to the person-centred approach to healthcare and they should not feel that these issues surrounding medicines need to wait for discussions at the annual health check. They should feel empowered to encourage dialogue around the administration of medicines and seek to engage with their local pharmacy on these matters.

Health Alert! campaign update

Following the Health Alert campaign article in the previous edition of the Journal, we thought we would provide you with an update.

The Department of Health and Social Care held a consultation in early 2019, to which we made a submission, on mandatory learning disability training for health and care professionals. We are pleased to report the Government has responded to the consultation by promising:

- All health and social care staff will receive relevant training on autism and learning disabilities
- A trial of the new staff training package will begin in 2020, backed by £1.4 million of government funding
- A series of trials will run first, followed by a wider roll-out
- People with learning disabilities and autism will be involved in the training

In November 2019, we published our Health Alert! campaign report Health care for people with Down's syndrome. The report is based on information from our members about their experiences of healthcare.

We are very grateful to members for coming forward with evidence. Some of our members reported very positive experiences of healthcare.

'We have excellent health care from our daughter's GP, Out of Hours and also from her heart consultant and rheumatologist.'

'I would like to say how much we have appreciated the care our son received. I know the NHS gets some bad press and not everyone has good experiences, but I felt it was important to report a positive experience!'

'Fingers crossed and touch wood all the professionals he has been involved with have always shown great care and understanding.'

'We have had nothing but excellent care from the NHS throughout his life (he is 21 years old) Our own local GPs have been exceptional in their care and consideration. We have nothing but praise and thanks for the care he has received.'

There have been many positive developments around awareness of the health conditions more common in people with Down's syndrome and their treatment since we started campaigning about health issues in the 1990s.

We acknowledge the significant contribution of the UK Down's Syndrome Medical Interest Group, with whom we work closely, towards these improvements in understanding and care.

Health professionals now have a duty to make reasonable adjustments for their patients with disabilities to ensure they have the same access to health care as everyone else.

For people with Down's syndrome, reasonable adjustments may include longer appointments, easy read information and support around consenting to treatment. You will find information about reasonable adjustments on our website.

However, we received too many reports describing poor experiences of healthcare.

Here is a summary of the concerns raised by families:

- Family carers feel their role in healthcare settings is ambiguous and that they are sometimes dismissed and ignored.
- Some family carers worry about what will happen to their relative's health when they are no longer around to provide support.

- Diagnostic overshadowing, assumptions about people with Down's syndrome coping with aftercare following surgery and disability discrimination
- Failures around recognising pain in, and managing pain for, people with Down's syndrome
- Lack of empathy/compassion from healthcare staff for their family member with Down's syndrome
- Lack of understanding of Down's syndrome and people's communication needs
- Lack of understanding of statutory guidance around decision-making and mental capacity
- Lack of reasonable adjustments in healthcare
- Poor communication by health professionals with families, each other and with their patients with Down's syndrome.

The Health Alert! report has been sent to key stakeholders, it has been shared via social media, and prior to the 2019 election we urged members to ask their local MP/local candidates what they would do to address the issues raised in the report.

We continue to be very concerned about recent high-profile cases of preventable deaths of people with Down's syndrome.

Towards the end of 2019 we were saddened to receive a report from a sibling about the death of her brother, who was in his early forties.

The sibling told us about their serious concerns relating to the care their brother received prior to his death. We have written to the Chief Executive of the relevant NHS Trust raising those concerns and offering to work with the Trust to ensure people with Down's

syndrome receive equitable, timely and high-quality healthcare. The Trust has undertaken to investigate the circumstances surrounding the man's death.

Please be assured the DSA will continue to inform, raise awareness and campaign about the health needs of people with Down's syndrome and their right to equitable and

timely healthcare.

In 2020 we will be developing a new Down's syndrome specific training package for health care professionals.

We are always looking to hear from our members about their experiences of accessing health care (good or bad), as they help us campaign for change in cases like this. You can share your stories via email to info@downs-syndrome.org.uk or by calling our Helpline and speaking to one of Information Officers on 0333 1212 300.

The Learning Profile as a Recipe for Success

Beth Pickard

Instrumental Tuition for Musicians Who Have Down's syndrome

Introduction

This article reflects on a recent research report published in the Research Studies in Music Education journal detailing my approach to instrumental tuition for musicians who have Down's syndrome (Pickard, 2019).

It is hoped that this article will be an accessible summary of the research and the proposed framework which can be explored by musicians with Down's syndrome, their families, supporters, and music tutors. For this article I have chosen to focus on one musician, Olivia, who along with her family has given consent to be part of this article.

The Learning Profile

This article, along with my approach to instrumental tuition, is informed by the evidence-based understanding that individuals with Down's syndrome tend to learn in accordance with a particular learning profile (Bird, Alton and Mackinnon, 2018). This profile suggests a range of strengths and challenges which individuals with Down's syndrome may experience, to a greater or lesser extent, in educational contexts.

The profile includes:

- Relative strength in visual memory – children might remember things they see better than things they hear.
- Relative weakness in auditory memory – children might not remember things they hear as well as things they see.
- Strength in social skills and non-verbal communication – good at forming and maintaining relationships and reading body language.
- Potential sensory impairments – children might need glasses, hearing aids; tools for accessing audio/visual information.
- Delayed motor skills – children might reach milestones later, or have fine and gross motor skills that are not as developed as their peers.
- Learning disability – children might learn slightly more slowly or in a slightly different way.

Within the discipline of Critical Disability Studies, approaches centred around a musician's disability can be seen as negative since they may focus on deficiency rather than ability (Penketh, 2016); this is a stance I am eager to avoid. My approach seeks

to develop an interactional understanding of disability (Traustadóttir, 2004; cited in Goodley, 2017), thinking about the interaction between the music student who has Down's syndrome, the music teacher and the learning environment and strategies employed. It is hoped that while this approach draws from the evidence-base of the educational experiences of children with Down's syndrome, it may widen access to music education for many, since *"rarely do music educators find that instructional initiatives benefit only the students for whom they were designed"* (Darrow, 2015, p. 31).

Applying the Learning Profile to Instrumental Tuition

As noted, I am eager to consider the learning profile of children with Down's syndrome as a recipe for success, and a potential framework for developing a constructive and successful approach to music practice. In applying this evidence-based learning profile to my approach to instrumental tuition, I have devised the following summary of ways of enabling pupils with Down's syndrome to successfully access instrumental tuition:

Learning Profile of Children with Down's syndrome

Relative strength in visual memory over auditory memory

Stronger receptive language skills than expressive language skills

Potentially delayed motor skills and low muscle tone

Strong non-verbal communication and social skills

Learning disability

Potential sensory impairments

Example of Application in Instrumental Lesson

Present information visually such as colour coded notation, aesthetically attractive materials and resources. Utilise the instrument to demonstrate rather than relying on verbal explanations. Avoid over-reliance on auditory information. Present auditory information in shorter chunks, accompanied by sign-supported communication and visual information wherever possible.

Maintain awareness that receptive language may be stronger than expressive language and this could impact on the structure and content of the verbal dialogue. Utilising sign-supported communication could support both receptive and expressive communication and questions could be structured in such a way that answers could be given through choice making rather than relying on breadth of expressive vocabulary.

Specific games and activities could be developed which build on social skills, to strengthen fine motor control and develop muscle tone for instrumental performance.

Consider utilising games and playful strategies to deliver information and maximise use of gesture and non-verbal communication throughout the teaching.

Consider the pace when introducing new material and develop opportunities for repetition and consolidation. Approach concepts from multiple perspectives and modalities, with time for processing. Flexibility is necessary to respond to the experience of the individual.

Ensure any visual materials are accessible in size, clarity and perhaps tactility. Ensure auditory information is amplified if necessary and there are accessible means of communication and engagement.

(Pickard, 2019, p. 4)

In order to further illustrate how this approach may operate in practice, I will present a short case study about Olivia's piano lessons, with her and her family's consent.

Olivia's Piano Lessons

When we began working together, Olivia was a cheeky, energetic eight year old girl who loved musical theatre and happened to have Down's syndrome. Olivia was eager to learn to play familiar melodies and songs she enjoyed on the piano, and this was the stimulus for our work together. We initially discussed Olivia's aspirations and how we might achieve these together.

Through my background in education and support work I had already read about the potential learning profile of children with Down's syndrome, and was learning about empowerment, ableism and the social model of disability through my research in Critical Disability

Studies. I was eager to develop a provision that was accessible, meaningful and fun for Olivia, which reflected her potential learning profile as well as a respectful and empowering philosophy.

Elements of the learning profile were apparent from the outset, such as Olivia's low muscle tone making her fingers floppy. We engaged her strong social skills to play games which strengthened her fine motor skills, which then prepared her for increasingly technical playing in the future. It was also apparent from the outset that Olivia responded well to simple, clear communication, accompanied by simple sign language. This evidences her stronger visual memory over her weaker auditory memory, and a successful strategy for enabling accessible communication throughout.

We learned some key signs together, using SignAlong

(SignAlong, 2016) and developed an expressive repertoire with which we communicated effectively.

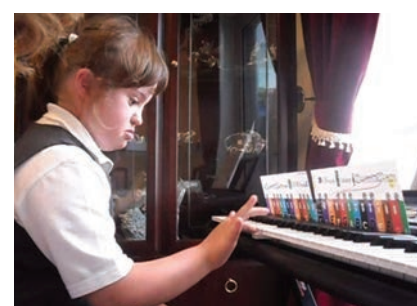


Figure 1 - Olivia explores the 'Colour Muse' method which denotes each note by a colour

Elements of music theory such as traditional notation were challenging at the outset, and we found that Michael Maxwell-Steer's 'Colour Muse' approach was highly accessible in its fun, visual and colourful aesthetic (Steer, 2016). Through this method, a family of dinosaurs represent different note values, and a coloured panel is placed behind the keyboard

to make the individual note heads on the stave increasingly identifiable.

Over the ensuing two years I developed a repertoire of individually designed worksheets for Olivia, drawing from the 'Colour Muse' method but incorporating letter names which Olivia found more accessible than the notes on the stave initially. I incorporated appealing images of the singers of the pop song or the cast of the musical to which the song belonged, or other imagery that would appeal to Olivia.

Through this method we developed an increasingly complex repertoire, incorporating elements of music theory such as time signatures, finger patterns and dynamics. Through a series of accompanying worksheets, Olivia explored these elements of music theory, at a pace appropriate to her learning.

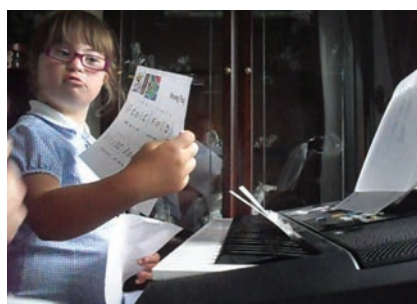


Figure 2 – Olivia explores individually designed worksheets

We explored a range of approaches to music making, including turn taking, performing for each other, playing at alternating ends of the keyboard, singing along, playing in unison and improvising to a stimulus. This range of approaches enabled *"multiple means of representation... multiple means of action and expression... and multiple means of engagement"* (Darrow and Adamek, 2012; cited in Darrow, 2015, p. 215) which allowed for significant repetition and consolidation.

Ownership was given to Olivia to dictate the pace of her learning, as we collaboratively set goals for our work. Olivia particularly wanted to play familiar melodies, aiming to play "both hands together". This provided an achievable target for

us to work towards, and when we reached this milestone I was able to present Olivia with a 'Melody' certificate (Melody, No Date). This flexible, editable certification scheme enabled Olivia to engage in celebration of her achievements with family and peers, in a way that was relevant to her learning.

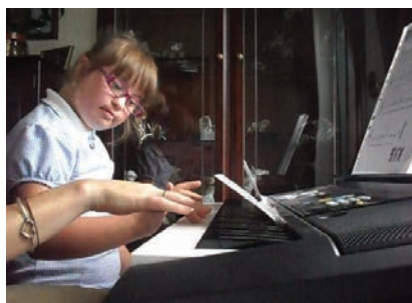


Figure 3 – Olivia and I explore the keyboard and different hand shapes together

Learning the piano enabled Olivia to experience an *"able identity"* (Magee, 2002, p. 179) and to transform her identity from 'disabled pupil' to 'musician', a concept Lubet (2015) terms 'social confluence'.

Olivia and I shared an enjoyable musical journey over several years, eventually reaching what would be the preliminary stages of a traditional music syllabus. However, the impact on Olivia's musical, social and emotional development was considerable, as well as incidental academic learning about numeracy and other concepts.



Figure 4 – 'Melody' Certificate

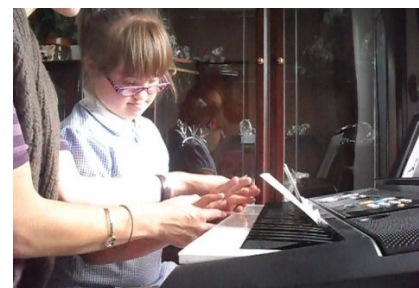
Conclusion

This article has demonstrated the potential relevance of the evidence-based learning profile of children with Down's syndrome (Bird, Alton and Buckley, 2018) to instrumental tuition, and proposed a framework for developing successful and enjoyable music lessons. The case study with Olivia demonstrates practical ways in which these ideas can be explored in practice by any skilled music teacher, and also illustrates what is possible when we approach instrumental tuition from the valid perspective of the musician. It is hoped that this approach can challenge a medicalised gaze in educational and therapeutic practice, offering an affirmative interpretation of disability.

The skills required of the practitioner were mostly patience and a commitment to the student's learning aspirations. Instrumental teaching for students with Down's syndrome does not necessarily require specialist training or qualifications. For parents or support workers seeking instrumental tuition, I would advocate approaching a good tutor in your local area, and sharing some of this information as a starting point for your musical journey. I hope this article along with the research report might give mainstream music teachers the confidence to develop their provision and to enjoy the privilege of learning from musicians who have Down's syndrome.

Acknowledgements

Thank you to Olivia and her family for the pleasure and privilege of working with them over several years, and for kindly giving the permission to share this work.



Congratulations to Olivia who continues to excel in creative activities and challenge assumptions about disability and the arts.

References

- Bird, G., Alton, S. & Mackinnon, C. (2018), *Accessing the Curriculum – Strategies for Differentiation for Pupils with Down Syndrome* (2nd Edn), Down Syndrome Educational Trust
- Darrow, A. A. (2015), 'Ableism and Social Justice: Rethinking Disability in Music Education', in Benedict, C., Schmidt, P., Spruce, G. and Woodford, P. (Eds), *The Oxford Handbook of Social Justice in Music Education*, Oxford: Oxford University Press, p. 204 – 220
- Goodley, D. (2017), *Disability Studies: An Interdisciplinary Introduction* (2nd Edn), Thousand Oaks, California: Sage Publication Inc.
- Kristiansen, K. and Traustadóttir, R. (Eds) (2004), *Gender and Disability Research in the Nordic Countries*, Lund, Sweden: Studentlitterature
- Magee, W. (2002), 'Disability and Identity in Music Therapy', In Macdonald, R., Hargreaves, D. and Miell, D. (Eds.), *Musical Identities*, Oxford: Oxford University Press, p. 179 – 186
- Melody (No Date), 'Certificates' [online], Available at <http://www.melodymusic.org.uk/certificates/4584922784> Accessed 19th June 2019
- Pickard, B. (2019), 'A Framework for Mediating Medical and Social Models of Disability in Instrumental Teaching for Children with Down's Syndrome', *Research Studies in Music Education*, Online First, p. 1 – 19, DOI: 10.1177/1321103X19855416
- Penketh, C. (2016), 'Creative Subjects? Critically Documenting Art Education and Disability' In Bolt, D., *Changing Social Attitudes Towards Disability: Perspectives From Historical, Cultural and Educational Studies*, London, UK: Routledge, p. 132 – 141
- SignAlong (2016). SignAlong: The Communication Charity. Retrieved from <http://www.signalong.org.uk/>
- Steer, M. (2016). Colour muse. Retrieved from <http://msteer.co.uk/edu/1ndexEdu.htm>

Fundraising and Trusts



Can you #Challenge50?

2020 is a special year for the DSA and we've upgraded our much loved Challenge 21 to the sparkling, new #Challenge50. The challenges are designed to be accessible to anyone, anywhere and most importantly – good fun!

We're inviting individuals and communities to take on the tasks together or on their own. So, head on over to our website to see some of our fantastic #Challenge50 ideas and see how you can have fun and support DSA during our 50th Anniversary year.

50th Anniversary Treks

This year we are going to be at some great trek events as a charity partner of Action Challenge.

To mark our Anniversary we want to get teams together for each event – the London 2 Brighton Challenge, the Thames Path Challenge and the Thames Bridges Trek – so that we can make each fun-filled challenge a real celebration.

There are different distance options and you'll be supported along the way by Action Challenge and your Team 21 team mates.



Check out our website for more information and sign up!

Hays Travel Foundation supports WorkFit® South



Earlier this year we were delighted to be awarded a grant of £2,500 from Hays Travel Foundation. The grant was given to support young people (under 25 years old) with Down's syndrome who use our WorkFit® service in the South. The mission statement of the Foundation is 'To help young people achieve and be the best that they can be in their health, sport, the arts and education'

Our South West Fundraiser, Becky met with staff from the Newton Abbot branch and was presented with the cheque at our offices in Newton Abbot. Thank you Hays Travel Foundation.

Damon Hill Golf Classic and Gala Dinner with Michael Caines

Would Damon Hill OBE stand for Prime Minister? What does Michael Caines MBE, DL serve up at home on a Saturday night? Just two of the burning questions audience members had for the celebrity pair at our special charity event in Devon.

Both former F1 Champion Damon, who has a son with Down's syndrome, and Michelin-starred chef Michael, are patrons of the Down's Syndrome Association and Down Syndrome International.

"I was delighted to be able to attend the golf day and evening dinner again this year, which supports two charities close to my heart. The event was well organised and well attended, and of course it is always lovely to spend time in beautiful Devon. The food was sensational and having Michael Caines and Lympstone Manor's support, is greatly appreciated and enjoyed. I hope next year that we can have more evening guests and can reach out to more golf hole sponsors."

Damon Hill, OBE

Teams of golfers, including Damon, enjoyed 18 holes of golf and friendly competition. The winning team was a group of four ladies hailing from Perranporth Golf Club and the individual winner was Jack Southcott from The Exeter.

In the evening guests enjoyed a Salcombe Gin drinks reception and four-course dinner created by Michael Caines and Exeter Golf and Country Club's head chef, Adam Little, with wines perfectly paired to each course.

A charity auction chaired by 'Homes Under the Hammer' auctioneer Graham Barton – complete with trademark striped blazer – helped the funds roll in. Michael Caines said:

"This year's gala dinner was absolutely fantastic, and it was a joy to work alongside Adam Little and create such a beautiful menu. I especially enjoyed the Q&A session with myself and

Damon, giving people the chance to ask us anything and everything. Some great auction prizes and competitive bidding helped raise lots of money – I'm already thinking of ways to make it even bigger and better next year!"

The event would not have been as successful as it was without the support of: Lympstone Manor, Exeter Golf and Country Club, The Exeter, Pen Life Associates, Valley Motorsport Promotions, Boulter and Bowen Wealth Care, Salcombe Gin, Tolchards, Flying Fish Winery, Lyme Bay Winery, Regency-Wines, Forest Produce Devon, Christopher Piper Wines & M.C.Kelly (Elston Farm)



Damon Hill OBE and his team at our annual golf day. Photograph by Matt Round Photography

My 21-hour charity football event

By Rob Hardiman

It's January 2019...New-year, new-me. I sit down every January to plan the year ahead and this year I was determined to run my very own Charity event. And selecting the Down's Syndrome Association was the easiest choice in the world.

As a young boy, my parents would often have my uncle Shaun to stay over for weekends and as an only child this was something I always thoroughly looked forward to. From an early age I'd had a special relationship with my uncle Shaun and loved going to meet him at his work, where he would keep our local leisure centre cafe absolutely spotless. 25 years on and I am now able to have Shaun for the weekend, and I still have that same special feeling when I know he's coming to stay. Our time together consists of fun activities such as snooker, swimming, bowling, golf and baking, but Shaun also enjoys some chilled time too and loves reading newspapers and must not miss EastEnders.

Seeing Shaun hard at work and taking part in so many activities exemplifies everything that the DSA stands for. And I feel so passionate about giving people with Down's syndrome the opportunity to live a full and rewarding life; to feel the importance and value of employment but also to enjoy the team spirit and thrills of sport. It is also incredibly important to me that the rest of society hold these same expectations and do not stereotype in any way.

So with charity chosen and ambition firmly in place, I was keen to follow the great work of "Challenge 21" and create an event that would push the mental and physical boundaries of as many people as possible. Following a very short brainstorming session our 21 Hour football tournament was born ... and the fun began.

In January my first port of call was convincing 24 friends and colleagues that playing football for 21 hours would be a) a good idea and b) be physically possible. Looking back at it now, I can see how I may have stumbled at the first block. But having finally managed to convince enough players and miraculously finding a date suitable to all, the ball was now in motion.

Following on from this I met with Laura McIntee from the Fundraising Team as the DSA to discuss the intricacies of our 21-hour football tournament. I was overwhelmed by the support I received at the Langdon Down Centre. The whole DSA team have been absolutely fantastic to work with; whether it was Emma passing on valuable knowledge on the legal aspects of event organising or Andrea helping with communications – I could not have done this without them.

Next we secured the services of St Georges Park, the home of the English FA, for our venue. All that was left was the finer details of event planning and getting to work raising as much money as possible. With 24 budding footballers keen to play in the footsteps of our national heroes, commitment and excitement was high and I knew we could achieve something special.

With the help and support of my better half Kate we held everyone accountable to raising a minimum of £200 and worked tirelessly to keep motivation high. Kate and I lead by example by completing bucket collections at the Theatre Royal Nottingham and we cannot thank them enough for their efforts to maximise these collections. Slowly but surely our total was creeping up.

For the weeks leading up to the event everything was surprisingly

under control, but I had put my heart and soul into making this event truly special for everyone involved. We had organised medals, goodie bags for players, a food van for spectators, we had an official England changing room all kitted out, medical supplies were covered and the rules had been put down in writing.

I must admit it amazed me how much behind the scenes planning goes in to arranging an event like this and that there is always one more thing to do. But it all kind of snowballs along. And as every new idea pops up there is always someone on hand to help you and that was the joy of working alongside the DSA to make this a reality. No stone had been left unturned! Or so I thought. Until ITV news rang asking if they could come and film the event! The icing on the cake! A massive thank you to Andrea for our press release that made this possible.

27 September arrived, game day, and it was in the early hours that the 24 of us first met as a group in the Bobby Robson Changing room of St Georges Park. The changing room had been kitted out so that we felt like professional footballers. Motivational music was blaring out and the Physio was hard at work strapping up ankles. It felt like our World Cup final and it was only 5am. The first whistle blew, and the sentiment continued, we played as if it was really the World Cup final. This couldn't continue if we were to make the 21 hour target. The first 7 hours was played out at a great standard. Just as legs, inevitably, began to get heavy the ITV camera crew turned up – a secret I had kept from the rest of the group. Motivation rebooted!

For the next 4 hours everyone tried their best to get a goal on the

cameras and the atmosphere created with the support of spectators was amazing and for the first time I sat back and thought – we have done it.

With over 5 hours to go, and the standard of football now dubious at best, the skies darkened and the spectators left. It was time to dig into our final reserves. These last hours were made even tougher by the relentless rain that had evidently set in for the night. We pushed through till we were three hours closer to the final whistle, and although determination and willpower were winning, health and wellbeing were now in question. Players started to turn blue and, despite the multiple layers and raincoats, we were eventually forced to give in to the weather and call it off – we were so close!

In sheer disappointment I called in to the security team to advise them of our decision. I must now sincerely thank the St Georges Park team who then offered us the opportunity to finish the tournament on the indoor pitch which is normally strictly off limits to the public. Having seen what we had already put ourselves through, persevering in the pouring rain for so long, they knew what the right thing was to do. And we were back on!

With “*Three Lions*” blaring out, 24 sodden, broken men took to the pitch one last time to get it done! Motivational music pushed us through the long two hours that remained and as the first bars of “*We Are the Champions*” began to play...the final whistle was blown!! It was one of the most surreal and proudest moments of my life. We’d done it!

Watching 24 men, who had never been together in one group before, now embracing each other like brothers to mark the achievement symbolises the superhuman efforts that had just been displayed. Completely overwhelmed, I was unable to keep my emotions in check and was unable to respond to the chants of “*speech, speech, speech*” in a way that I wished. Instead we moved on to the prize



giving in which Jack Harvey won a trophy for the most goals in 21 hours and Sam Saragi and Sam Hopper won awards for their fantastic fundraising efforts. Our fundraising total had been kept completely secret as an added form of motivation...as our final team photo was taken as we were presented with a cheque for a staggering £9,523.34.

My January goal was now a September dream.

With legs like lead and my emotions still running high, I woke up late the next day to find out that our fundraising total on justgiving.com had now topped the £10,000 mark. Suddenly, I was pain free. I was numb. Never in my wildest dreams, back when I was writing my New Year’s resolutions, could I have imagined such an amazing total. It just goes to show that if you have an idea, no matter how big or small: write it down, take action, ask for help along the way and just roll with it – something special awaits at the end.

Having now had time to recover I would like to take this opportunity to thank all the players who showed strength, determination and, more importantly, humour through an experience that was, by the end, sheer pain. Extended thanks must go to Kirsty and Shivanie from Ascenti Physiotherapy for helping us out with sports massage throughout the day and to all the supporters who came to push us through. We

couldn’t have done it without you. And to Kate Barnett, who took the role of event organiser on the day. The tournament ran so smoothly and her passion and enthusiasm to control 24 tired and grumpy men was truly heroic. For her to stay awake and embrace the challenge with us whilst boosting moral and smashing the social media helped achieve this amazing feat.

It meant the world to me to have my uncle Shaun at St Georges Park to share in such a special day. He is a constant inspiration to me and I am really glad that we could give him a moment of fame in front of the ITV cameras...although we can’t go anywhere now without him giving out his autograph!

As 2019 ended, I reflected back on the year with great pride and great memories. But it was also the time to start planning for 2020...and now that Challenge 21 has become Challenge 50 (to reflect the DSA’s 50th anniversary). I now have a lot of worried friends keeping their distance.



Corporates



50th Anniversary Appeal

The DSA is turning 50 in 2020!

For the last 50 years the DSA has been at the forefront of changing attitudes, educating people about the condition and providing services and resources to support both people with Down's syndrome and their families, carers and health professionals.

Support from companies and organisations is vital to enable us to continue our work in transforming the lives of children and adults with Down's syndrome. We are inviting

companies to support the DSA's special 50th anniversary appeal with a view to getting 50 companies onboard to support the charity with financial donations.

If you have any contacts at companies who would welcome a conversation from the DSA for possible support do let us know by simply emailing info@downs-syndrome.org.uk

Their support could transform the lives of many more children and young people with Down's syndrome.

Many thanks to...

In 2019 we had some fantastic support from companies which has helped the DSA to run the services and programmes for thousands of children and adults with Down's syndrome.

Our sincere thanks go to all the companies who have supported the DSA in 2019. The following are two companies who have shown their support for the charity.



For the first time the DSA was selected as one of the charities for the innovative Co-op Local Community Fund which aims to provide funds for local projects.

Customers who are members of the Co-op membership scheme had an opportunity to vote for selected local projects and charities when they purchased goods at the local Co-ops to the Teddington store.

Through the support of customers taking part in the Community Fund scheme, an amazing amount of £7,245 was raised for the DSA.

The money will go towards the



Pictured are members of the Down2Earth group showing their thanks and appreciation for the support from the fantastic Co-op Community Fund.

Having a Voice® advocacy programme for people with Down's syndrome and Down2Earth, the Teddington based Having a Voice® group.

Thanks to Buchanan and Victoria Agutter

Support from Buchanan and Victoria Agutter led to a generous donation of £4810 which will make a difference to the work of the DSA. Our thanks go to Buchanan and Victoria Agutter.

Waitrose Community Matters

Just as the DSA is approaching a milestone year, Waitrose is celebrating 10 years of Community Matters. Community Matters is the longest running community scheme of its kind and for over 10 years has supported 100,000 local community causes.

Over the years we have had fantastic support from Waitrose stores and have been featured in Community Matters in 12 of their stores including Twickenham, Exeter and Walbrook in London. In 2019 over £2800 has been raised

for the DSA through the scheme and our sincere thanks go to Waitrose for this amazing opportunity.

We are always looking to extend support for the DSA through Community Matters so let us know if you have a local Waitrose which you could nominate the DSA for the innovative Community Matters scheme by contacting info@downs-syndrome.org.uk.

WAITROSE
& PARTNERS

Trusts

Trust income continues to be a vital element of our fundraising activities and we would like to thank our wonderful Trusts and Foundations for their support, which has been instrumental in helping us to provide vital support to our members, their families, and everyone else who accesses our various services.

Over the years, the DSA has been fortunate to form ties with some incredible organisations that have supported our work with their time, money and valuable insight, helping us grow our network and support more and more families who need us. In this issue of the Journal, we would like to thank two very special Trusts that have reaffirmed their support in recent months, backing some of our key projects.

Since its first grant to the DSA in 1994, the Hospital Saturday Fund (HSF) has been a constant ally. They have supported some of the vital education projects through the 90s and the noughties. In 2015, a grant of £10,000 from the HSF gave our Tell-it-Right™ campaign a significant boost helping us not only reach greater numbers of antenatal professionals and hospitals but also attracting future funding for the project. Their most recent grant in October 2019 has gone toward

the provision of Resilient Carers, a DSA project aimed at helping parents and carers build resilience by alleviating stress and anxiety, addressing isolation and loneliness. The project offers practical support and specialist advice to parents and carers of children and adults with Down's syndrome.

We also want to thank the Peter Harrison Foundation for their incredible generosity, pledging a three-year support to DSAActive, helping this vital project reach the next level. Their grant will help us to launch newer sports such as rugby, cricket, sailing and athletics for players and participants with Down's syndrome; expand existing

sessions and attract new players, and help the DSAActive team deliver specialist condition-specific training to more coaches.

The Foundation is committed to helping organisations that use sports as a means of self-development, including disability sport.

Since its launch in 1999, they have made 1,306 grants to 806 charities, totalling an incredible £44,663,041!

If you are a Trustee of a Charitable Trust or Foundation and would like to find out more about how you can make a real and measurable difference to young people with Down's syndrome, please contact us.



A brief history of Down's Syndrome North East (DSNE)

We formed as the North East Branch of the DBA (Down's Babies Association) in July 1977. The inaugural meeting was held at Low Fell Methodist Church Hall which became the venue for most of our early meetings and events. The Chair was Alan Phillips who lived locally. Our Branch covered the North East of England from the Scottish border to Teesside and after several years was extended to include Cumbria. After a couple of years the DBA changed its name to the DCA, the Down's Children's Association and then after a few more years it changed again to the current name of the Down's Syndrome Association.

During the early years we had a variety of important speakers at our AGMs and half-yearly meetings. The founder of the Association, Rex Brinkworth, came twice, whilst others included Roy McConkey from Northern Ireland and Sue Buckley from Portsmouth. Meetings and events were held in a variety of locations across the region. From the beginning we published a quarterly Newsletter and when we became an independent group it was christened 'The Grapevine'.

In 2002 (along with other branches of the DSA) we were asked if we would like to become an independent charity. We consulted our members and when a large majority said 'yes' two longstanding members, Michael Kirk and Ken Moore, created DSNE from the NE Branch of the DSA in 2003.

We were, and still are, very grateful to the DSA and the Charity Commission for their support and advice in creating the formal structure for our charity. That structure was vital to ensure that we started off on the right foot. We secured the support of the Duchess of Northumberland, Carol Malia (news presenter BBC TV), and Bill Midgley OBE (Chairman Durham County

Cricket Club) who agreed to be Patrons of DSNE.

We are and have always been ambitious for DSNE and on 4 May 2003 had a Grand Launch at the Stadium of Light (home of Sunderland AFC) to ensure that we would be noticed. There is no doubt that such an elaborate occasion was justified as our membership increased at quite a rate.

We already had some very popular activities in place. The wonderful facilities at the Calvert Trust Kielder Water, Northumberland, allowed us to run swimming in the pool, sailing on the reservoir, canoeing, bike riding and Orienteering in the forest, Archery and horse riding.

Some new local groups were starting up but we needed some help with developing this. In 2005 we applied to the Big Lottery Fund who awarded us £135,000 spread over 3 + years.

We recruited and trained two Development Officers (both called Rachel!) and our area was divided between them. Their brief was to raise awareness of DSNE, increase membership, and recruit and train more volunteers to deliver our plans across our area. After the funding finished we were well satisfied that we had achieved our objectives, with active local groups in Teesside, Darlington, Durham, Sunderland, Gateshead, Newcastle, and Northumberland.

During this period we decided to create a group for the over 18s. To discuss plans and ideas, we ran an open meeting in October 2007 for people from that age group. It was held in the Colin Milburn Lounge in Durham CCC. We had some fun and agreed to call the group "Circle of Friends".

Our Circle of Friends group have regular monthly meetings and enjoy tenpin bowling, indoor sports and

games, as well as parties. Once a year, several members join up with other groups under the watchful eye of Tin Arts, Durham, to perform a show at the Gala Theatre. Over the years they have become seasoned entertainers.

We have retained our link to the DSA as one of their affiliated local groups. Many events and activities that we run today have their roots in this long-standing connection, including:

- Inviting members to become volunteers.
- Development meetings for Committee and Volunteers.
- Publication of a Volunteers Guide Book.
- Arts and Crafts courses (known as BLAST) for older people with Down's syndrome.
- The creation of a separate group for adults with Down's syndrome, the Circle of Friends.
- The publication of a regular newsletter for adults with Down's syndrome, the Voicebox.
- The publication at regular intervals of a list detailing What's On Where.

AIMS

We try to promote the notion that whenever a member gets an idea to do something, they should always check that it is not done on a whim but is for the benefit of those with Down's syndrome, is feasible, affordable, is risk assessed, and meets the criteria set out in our Statement of Intent (see right).

Fundraising

We have had magnificent success with our fundraising over the years, from the Great North Run and other similar events through to smaller, but nonetheless very welcome, donations and coffee mornings.

Our Statement of Intent

To support people with Down's syndrome to live full and rewarding lives by providing information, support, facilities, services and opportunities that will maximise their participation in society and any other purposes connected with Down's syndrome within region.

As well as close family, we invite and encourage others to become Associate members of our organisation such as professionals in the fields of health, social services and education.

As a parent led voluntary organisation we strive to provide opportunities for all people with Down's syndrome – whatever their ability, and their families.

Here are what we aim to provide:-

- Opportunities to meet other parents who have a child with Down's syndrome.
- Advice and support.
- Conferences for parents, carers and professionals on all matters related to Down's syndrome.
- Regular newsletters which update members on recent and forthcoming events.
- Subsidised breaks at activity and leisure centres some of which specifically cater for those with special needs - eg. Calvert Trust and Moorhouse.
- Regular social events for all ages e.g. parties, theatre trips, music and sports events - e.g. monthly 10 pin bowling + Indoor games; Formal Balls.
- 'Look At Me' exhibition round the region.

Other past fundraising highlights include the 3 Peaks, Yorkshire 3 peaks, and round Kielder Ramble. We're getting more creative and professional about fundraising. In addition to all the traditional and vital activities (like bag packing and sponsored events) we're applying and winning grants from all sorts of sources. We have also got a 'Give As You Live' account which allows people to support us when they're shopping online. A local Rotary Club holds an annual sponsored swim event and as we're able to enter quite a lot of teams this is a great regular source of cash.

Our current position

We provide fun, social events for every one of our members, whatever their age or ability. These include monthly soft-play sessions, pantomime trips, outward bound weekends and art workshops. Our events give our members and their families the chance to network and develop strong friendships. We have an annual gala ball around World Down's Syndrome Day, followed by a family celebration day. Both have become extremely popular fixtures on our calendar.

We educate and support our members.

We promote a positive message about Down's syndrome, from providing medical professionals and trainees with up-to-date information about the condition to signposting people on how to get the right support from agencies.

Look at Me

One of the projects that really showcases the membership of our organisation is our recent 'Look at Me' exhibition.

Two years' ago 12 of our members, from babies a few months old to adults, took part in a photoshoot by a professional photographer. Each shot captured our members with a possession or in a pose that showed an interest or aspect of their personality.

We also ran a 'Look at Me' conference where we celebrated the diversity



of our members, some of whom spoke eloquently to a packed auditorium about their lives.

The photos were framed and turned into an exhibition which has been travelling all over the North East, displayed at a variety of venues and attracting lots of positive media coverage. 'Look at Me' typifies the diversity and personality of our membership and the hard work of all those involved with DSNE which has made it such a successful and longstanding support group.

JellyFish by Ben Weatherill

National Theatre 5 to 16 July 2019

Review by David O'Driscoll

The playwright Ben Weatherill described his play, Jellyfish, as a "messy, knotty romance ... about people we don't see fall in love very often".



Dominic (Nicky Priest) and Kelly (Sarah Gordy). Photographer - Helen Murray

Weatherill developed 'Jellyfish' for Sarah Gordy, as he has been "a big fan of Sarah for years." Gordy the star of many television shows including 'Casualty' and 'Call the Midwife' is an actress with Down's syndrome. Gordy plays Kelly, who falls in love with Neil, a man who does not have a disability, and their relationship is the focus of the play.

Kelly lives with her single mother, Agnes who is alarmed about this new development. Is Kelly consenting to this? Is Neil taking advantage of Kelly? Does Neil understand her vulnerability? Agnes tells Neil that she still needs to shave Kelly's legs, otherwise 'she will take chunks out of them!'

I did feel somewhat uneasy about their relationship and while I could see Kelly was able to give informed consent, such an important concept in today's rights-based services for people with learning disabilities, I wondered about the power dynamic

within their relationship. Agnes seemed to acknowledge Kelly's sexuality by arranging a date with Dominic, a man on the autistic spectrum. The scenes with Dominic have some of the best comedy in the play. Nicky Priest, who plays Dominic is a comedian as well as actor and judging by his deadpan delivery would be worth catching live. He also has autism.

While the play is funny it does not shy away from the painful aspects of disability, for example, Neil complains how every time he goes out with Kelly, people think he is her carer. They do not take seriously that Neil could be in a sexual relationship with a woman with Down's syndrome.

Neil also says that some of his co-workers see him as a 'pervert.' It raises the issue of the sexuality of people with disabilities...an issue we would, perhaps, rather not address. There is a saying in my psychotherapy world that there

are 'three secret' things we would rather not consider with people with learning disabilities: death, sex and the learning disability. The latter two get a good airing in this play. The script is sharp, witty, painful and rather provocative at times. It did have a clear conclusion. I enjoyed it. It was evident that the cast enjoyed it too. On the night I was there it got a well-deserved standing ovation.

Finally, I also liked the fact that one of our premium theatres is thinking of the needs of the audience and their experience. There was a notice on the way into the auditorium saying that the performance was going to be in a 'relaxed environment' the audience was able to 'come and go'.

There was a relaxing space away from the audience to which people could retreat. Interestingly, I did not see anyone leave and I also noticed a number of people with Down's syndrome in the audience. This is important as the National Theatre should be inclusive and I hope it's the start of more engagement with people with disability.

David O'Driscoll has been a psychoanalytic psychotherapist for the Hertfordshire Partnership University NHS Foundation Trust, Learning Disability service since 2000. He is a Visiting Research Fellow and Visiting Lecturer at the Centre for Learning Disability Research, Hertfordshire University. David has been a longstanding member of the Social History of Learning Disabilities group at the Open University and is the current chair of the Institute of Disability and Psychotherapy (IPD).

Langdon Down Museum

An exhibition by members of the Richmond and Kingston United Response art group was held in one of the exhibition rooms from August to December 2019.

The artwork included puppets, textiles, portraits, masks and sketch books. United Response provides a wide range of activities for those with learning disabilities.

www.facebook.com/URrichmondkingston

www.langdondownmuseum.org.uk



Book Review on 'Looking After My Eyes'

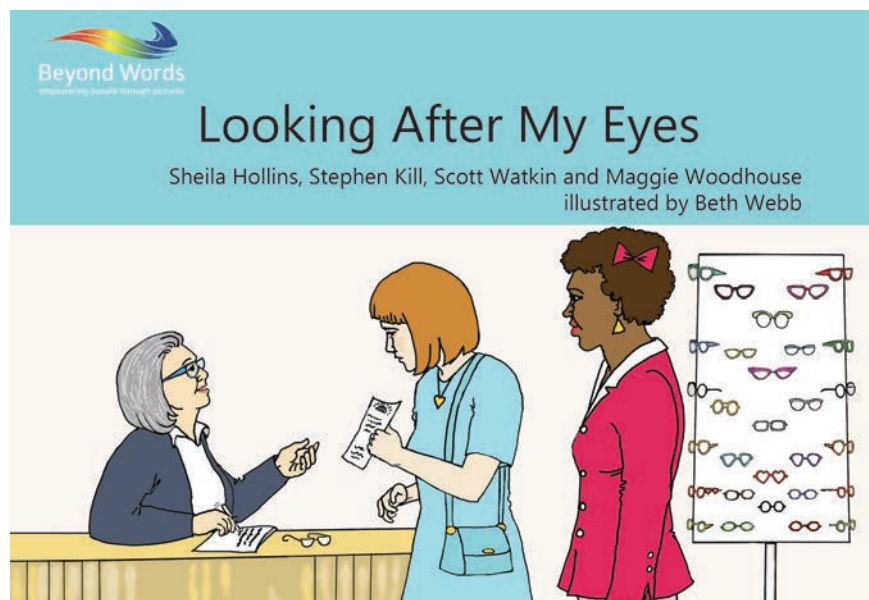
Khilna Gudhka

'Looking After My Eyes' is an excellent 'Books Beyond Words' publication.

Along with the other books under the 'Books Beyond Words' series, the story in 'Looking After My Eyes' is told through pictures instead of words. This is to enable those with a learning disability (who may find it harder to read words) to understand what going to an optician or a specialist eye hospital may involve.

I used this book with my daughter, who has learning difficulties and wears glasses, thus making her an ideal candidate for me to evaluate this book. As the book didn't have words, my daughter could use the language she knew in order for me to prompt discussion with her about who she could go to for help if there was a problem with her eyes, as well as recognise what can happen once she is at the optician or hospital. She thoroughly enjoyed reading this book, at the same time learning about how to 'look after her eyes'.

The pictures on all the pages were extremely clear, making it easier for the reader to comprehend what



the message on each page was focussing on. Additionally, a storyline and a guide on 'how to read the book' is included in this publication, which can support parents, carers or healthcare professionals working with individuals who have learning disabilities.

I would highly recommend GP practices, opticians as well as libraries having these books. This is to assist people with learning disabilities to easily access the books, so that they can be prepared before having an eye test, visiting a hospital or having an operation on the eyes.



Down's Syndrome Association

A Registered Charity No. 1061474

Helpline and Information Centre

0333 1212 300

info@downs-syndrome.org.uk

Our Information Officers are available to answer calls 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 with Down's syndrome shape our resources and help to inform our decisions through our network of Having a Voice® groups.

Parents and practitioners can also ask us questions on our closed Facebook groups.

Contact us for local parent support group details.

Training

training@downs-syndrome.org.uk

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



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.



LANGDON DOWN
MUSEUM OF
LEARNING
DISABILITY

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



www.langdondowncentre.org.uk

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

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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