



Memories & Stories

Celebrating
50 years of the
Down's Syndrome
Association

Celebrating in 'interesting times': 50 years of the Down's Syndrome Association

by Carol Boys

The new year 2020 started with great excitement at the DSA. We were completing the finishing touches to the calendar for our 50th anniversary celebrations. We had planned open days, sky-dives, family days, greater opportunities for face-to-face support, oral histories and of course our wonderful photographic exhibition!

The COVID-19 pandemic put paid to many of our plans but more importantly, it brought some very real and serious challenges for our whole community. Anxiety about health inequalities, support, access to education and services were just some of the concerns that families contacted us about. Our Helpline was incredibly busy at a time when there was so much uncertainty. As an organisation, we saw our income fall away overnight. Thankfully, we were able to keep our services running and we developed new ways to keep people connected. Our staff team rose to the challenges of the pandemic with resilience, creativity and energy.

We witnessed amazing acts of kindness and saw examples of fantastic care from health and social care professionals.

We were able to share stories of the generosity, grit, spirit, humour and adaptability of people who have Down's syndrome and their families and carers.

We felt great sadness for those who lost their loved ones to COVID 19.

Our amazing members and supporters responded to our appeal for financial support with outstanding generosity, being there for us at a time when the DSA needed it most.

The newly formed Our Voice team grew and flourished on-line. Developed out of our longstanding Having a Voice programme, Our Voice is a team of people who all have Down's syndrome. Our Voice work on projects and tell the DSA what they think about the work we do. Every member can participate and contribute to our work. We are really excited to have this group at the heart of everything that the DSA does. We will continue to build on this work.

One of the biggest challenges of 2020 for everyone was keeping fit, active and mentally well. DSEngage, our programme of online activities for people who have Down's syndrome, was born as we headed into lockdown number two, at a time when adults with Down's syndrome had been told that they were clinically extremely vulnerable. We are thrilled that these sessions have given so many people a chance to feel part of something, get some exercise and have some fun.

50 years has seen a lot of change, growth and shifts in both perspectives and attitudes. Our rich history, achievements and incredible stories that span those 50 years have given us great reason to celebrate this significant milestone. Our planned celebrations have continued in different forms albeit taking slightly longer to come to fruition. The beautiful photographs in this special publication are just one part of those celebrations and we're thrilled to be able to share them with you. You can also find the stories from our Oral History project on our website.

The DSA has an amazing membership that represents great diversity. This exhibition is a fantastic celebration of that diversity and I hope you enjoy it - we are proud to bring it to you! Thank you for your incredible support!

'Over the years that I've been a patron of the Down's Syndrome Association I've seen a lot of change; but the DSA continues to deliver inspiring projects, vital support and amazing opportunities for people who have Down's syndrome and their families and carers.'

— **Peter Davison**

'I'm proud to support the Down's Syndrome Associations work. They are there for everybody who has Down's syndrome as well as their families, whatever their age, whatever the issue. My brother has Down's syndrome and he has the most amazing life. He's a wicked bloke, and one of the reasons he has such an amazing life is because of the support he's had from the DSA.'

— **David Flatman**

'As a Patron of the Down's Syndrome Association, there is a mutual collaboration of mind, body and soul which brings me so much joy, and that feeling of togetherness makes everyone feel so good. Together we achieve more.'

— **Derrick Evans MBE aka Mr Motivator**

'I am really happy to be a Patron of the Down's Syndrome Association. I like to think I make parents more optimistic about the future of their children and we know that the Down's Syndrome Association is always there for them. I love my 'mini me's' and want my darling little ones to be all they can be.'

— **Sarah Gordy MBE**

'I don't know what I would have done over the years if I had not had the guidance and support of the DSA. I certainly don't feel that my son would have had all the opportunities in life that he has had.'

— **Fundraiser**

'Whenever I have had advice from the Down's Syndrome Association it has given me the confidence that I have been doing something right, and the motivation to carry on fighting to get the best for my son!'

— **Parent**

Rex Brinkworth 1929-1998

by Carol Boys



It has been over twenty years since Rex Brinkworth, founder of the Down's Syndrome Association, died. Ten years earlier, ill health had forced him to retire from active involvement in the work of the DSA. It is fair to say that his name and achievements may not be that familiar to many of our members today but I wanted to use the opportunity of this anniversary special edition to talk a little bit about his amazing achievements.

Rex grew up in a small Gloucestershire village where two adults who had Down's syndrome were very much included in the local community. This early experience must have made an impression on Rex because he went on to train as a teacher and by the 1950s he was working in a large Birmingham comprehensive as the Head of the Remedial Department...a precursor of today's SENCOs. Working with teenage pupils who struggled with their learning he developed a theory that lack of stimulation (early intervention as know it today) in infancy could be contributing to their difficulties.

In 1959 Jerome Lejeune, Marthe Gauthier and Raymond Turpin published the research that showed that Down's syndrome was caused by an extra chromosome. Rex was

inspired by the findings and continued his research '...on the respective effects of heredity and environment on intelligence if an environmental treatment...could be attempted.'

In 1965, Rex's youngest daughter Françoise was born. Françoise was diagnosed with Down's syndrome and was very poorly and hypotonic at birth. 'Though our paediatrician was positive and helpful, other judgements were that she would "never be more than a vegetable". After a short period of disarray, I began to test my theories on the fourth day of her life.' Rex was convinced that children with Down's syndrome at that time were '...bedevilled by severe under-expectation and that the conventionally negative medical prognosis had led parents to "give up" at once and not to provide their child with the intense environmental input required.'

Françoise's first year was, therefore, filled with affection, sensory stimulation, very careful consideration of her diet, special exercises, and the typical social interactions of any small baby. At one year old she was doing really well.

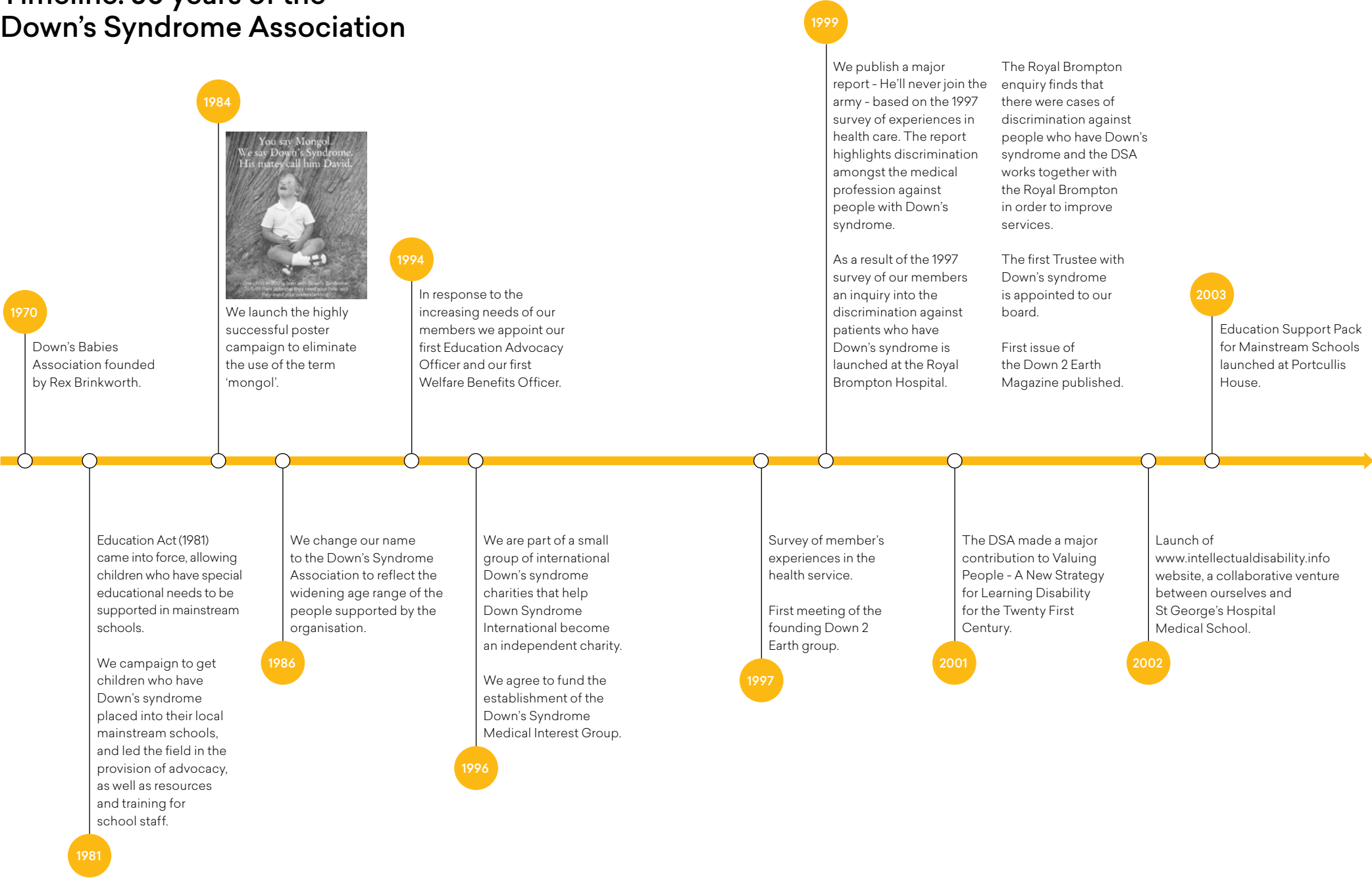
Rex went on to study Psychology at Birmingham University and quickly developed on his theories with families of babies and young children with Down's syndrome.

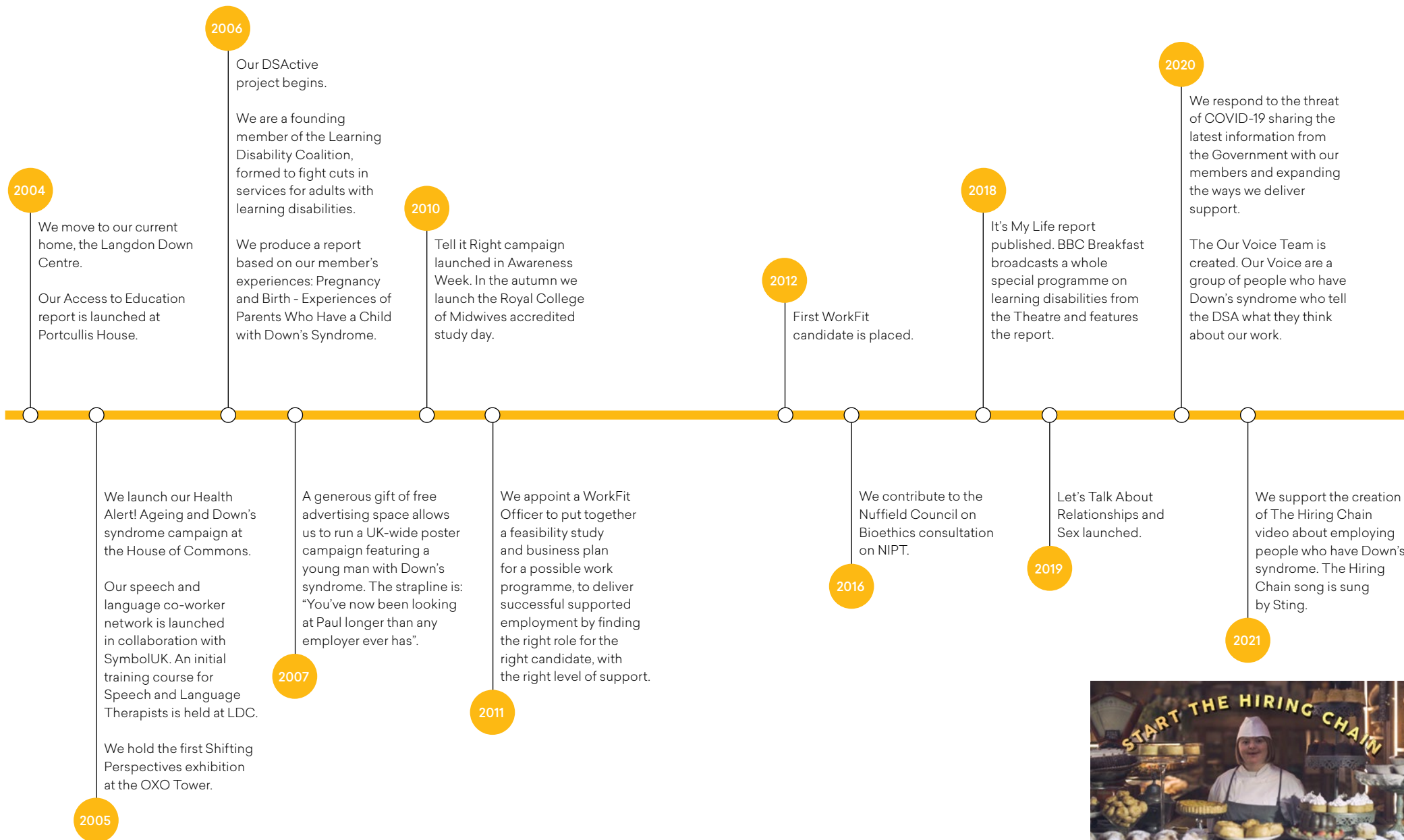
Rex carried out small studies of children who had been given stimulation both cognitive and nutritional and made comparisons with children who had received no extra input. By this time word had spread about the work that Rex was doing and families began to seek him out for advice and assessment. The formation of the Down's Babies Association at the Quinborne Centre in Birmingham provided a base where families could visit and contact by phone. Rex was seeing a lot of families and his research findings formed the basis of much of the advice, information and encouragement that was shared in the early years. Rex's commitment was unrelenting and he devoted an enormous amount of his time to his work with families.

The impact of Rex's ground-breaking work did make an enormous difference to the lives of people with Down's syndrome who were born in the late sixties, seventies and eighties. Rex challenged opinion and pioneered the idea that children who had Down's syndrome could learn, go to school and take their rightful place in society alongside everyone else. Rex gave hope to thousands of families and his work continues today at the DSA.

We are very grateful to Shirley Quemby, an early member of the DSA, for much of the detail included in this article. She's also written her own article about her experiences in the early days of the DSA.

Timeline: 50 years of the Down's Syndrome Association





The early years of the Down's Syndrome Association

by Shirley Quemby

Before our much-wanted first child, Roger, was born, in October 1971 (when I was over 30 and had already experienced miscarriages) I was aware I could give birth to what was then still called a 'mongol' baby. I had heard a speaker on Woman's Hour talking about teaching her own child before she began attending their village school.

Despite the general view that babies and children with Down's syndrome could not learn, I was determined to teach Roger everything that typical babies achieved, helped by local families with young children.

My brother lived nearby. Outside their daughter's school my sister-in-law met Felicity Stafford. Felicity's daughter Jenny, who was two and a half, had Down's syndrome. They had recently moved from Birmingham where they knew Rex Brinkworth, founder of the then Down's Babies Association (later to become the Down's Children's Association and today, the Down's Syndrome Association).

We obtained Rex's publications, which included advice on vitamins and minerals to combat low absorption, but more importantly, practical advice and ideas of ways to encourage Roger to develop his physical and cognitive skills. Rex gave us a programme of exercises and activities designed to encourage young babies and children with Down's syndrome to reach their full potential.

Rex's message, that babies with Down's syndrome could learn and develop well, contrary to the low expectations of the world in general, many medical professionals and even some parents, was hugely newsworthy at the time. Rex was on national TV; magazines published articles by Felicity; and I was interviewed on BBC Radio London.

We started the first Down's Babies Association branch in Cheam in June 1973 as there was no local support for new parents. Parents came from across South East England, officers were appointed. We held open days for families and a regular



Roger pictured with his sisters, Oct 1975

newsletter began. Isabel Gordon, a member of The National Council of Women in Epsom, joined us and ran the branch for ten years while our children were little. Regular talks were given by Isabel and Felicity to students, health visitors and other organisations.

Our daughter was born just before Roger's second birthday and he took great interest in teaching her. By the time his second sister was born, 17 months later, I was teaching Roger to read with flash cards. He progressed enthusiastically and his speech improved. Being the eldest, Roger enjoyed playing school teacher!

In February 1976 the BBC made a TV film for its Open Door series. A doctor and parent in Southend who were helping new parents with Rex's advice on early stimulation were in this film as were Felicity, Jenny and ourselves. Jenny was cheered ascending her school climbing frame!

Newsletters by Robert Stafford, Isabel Gordon and Elisabeth Blackwell (mother of Rebecca, born 1970) included invaluable ideas. Clear drawings filled the pages of every edition showing active babies and simple toys, providing

welcome advice to parents working alone at home. Each newsletter also included contact details of members who were ready to help any new parents seeking friendly advice or a local group.

For our half-yearly open meetings, school or church halls were hired by DBA volunteers. Speakers provided guidance on education, health and other aspects of developing independence, even how to teach the 'pincer grip'. Dr Janet Carr OBE, who had been researching a cohort of babies with Down's syndrome since 1964, advised on behaviour.

Members created smaller local parent groups to share this challenging - yet rewarding - childhood. Most groups were represented at branch committee meetings so the branch founders came to know parents across the south east leading to half-yearly meetings being set up in their areas.

Friends raised funds for postage, printing and hire of halls. Stalls were held at fêtes to publicise the Association and change the public's perceptions of children who had Down's syndrome. Although attitudes and language were slow to change, donations came in.

In 1975 an international Special Education Conference was held at Kent University. Our branch displayed a screen of photographs at the event and the delegates from Norway and Japan requested translations of Rex Brinkworth's ground-breaking work.

By 1978 the branch office had moved to The Old Rectory beside Carshalton Ponds. Committee meetings were held here for which Isabel wrote the minutes for ten years then I produced them until 2016.

Down's Children's Association meetings were held at the Quinborne Centre in Birmingham, led by Rex, who delivered detailed practical information for parents who wanted to support their child to develop. By 1978 more branches were founded, all spreading Rex's vital message and guidance; that babies and children with Down's syndrome could learn and, as Rex stressed, will go on learning.

Felicity's son was dyslexic. Jean Shergold, the teacher who helped him, then took an interest in Jenny and the children of other local members, concentrating on the needs of each one. When a child became bored, to maintain interest in practising for the lesson she would move the coloured pencil and paper to the floor - to add fun to the task! Probably the two



Roger pictured with his sisters, Nov 1976

lessons learnt by all parents, then and now, is to make learning fun and to teach visually as far as possible.

Jean continued to be involved with the branch. As children who had Down's syndrome were accepted into mainstream reception classes, we were called in to advise teachers. Jean and I gave talks during lunch breaks. We noted their problems then wrote the first information sheet for teachers incorporating advice to help the worried, sometimes even frightened, teachers who were going to have a child who had Down's syndrome in their class for the first time. It was published by the Down's Children's Association as a booklet, credited to myself and Jean.

An immense debt is owed to Rex Brinkworth MBE and his small team in Birmingham enhanced by Felicity Gresser (formerly Stafford) and her team in Cheam and DSA volunteers across the country.

Memories & Stories: An exhibition celebrating 50 years of the Down's Syndrome Association

This beautiful collection of portraits demonstrates the changes that have been achieved for people with Down's syndrome over the last 50 years. They tell wonderful stories of people thriving in their own communities and being valued members of them.

We captured these images and stories so that lessons can be learnt and the successes repeated and built upon. They shine a light on people with Down's syndrome, they let their voices be heard and they shatter any preconceptions to show how people have flourished over the last 50 years.

This series of portraits was shot between lockdowns during 2020 and 2021.



Alan Hicks

Alan lives with his mum and works in the café at Leep1. He dreams of being an actor. Alan is proud to have Down's syndrome and views his work as a Steward for the People's Parliament as vital for getting the voices of people with learning disabilities heard.

Photograph by Niall McDiarmid



Andrew Morris

Andrew loves music, exercising and watching television. He's great at telling stories and enjoys going to art and drama classes. Andrew also has a passion for cooking.

Photograph by Enda Bowe



Anne-Mary Haward-Smith

Anne-Mary grew up in Devon where she lived with her mum in a Shales Lives family. She has recently moved to Scotland to be near her extended family. Anne-Mary loves dancing, singing, crafts and socialising.

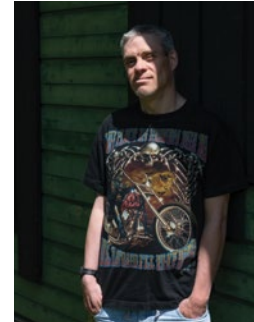
Photograph by Richard Bailey



Anya Souza

Anya lives in London with Paul, her partner of 35 years. Anya has been a Trustee of the Down's Syndrome Association for more than 25 years. She feels passionately about fighting for the rights of people who have Down's syndrome and keeping them up to date with issues that impact their lives.

Photograph by Laura Pannack



Barry Humphreys

Barry lives in a flat with two friends and works in the local coffee shop one day a week. He enjoys wrestling and spending time on his iPad.

Photograph by Richard Bailey



Ben Fogg

Ben has been supported by MacIntyre most of his life and now lives in Milton Keynes. Ben recently turned 50 and had a fabulous pride/rainbow themed party with drag queen performers.

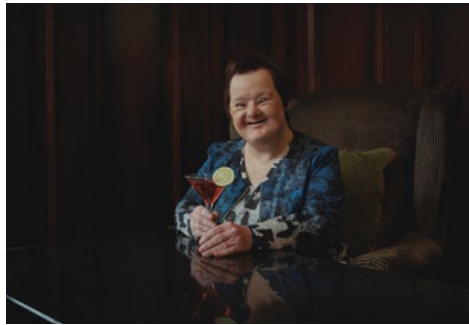
Photograph by Richard Bailey



Berge Kanikian

Berge feels passionately about making sure his voice, and the voice of his peers, are heard. As a Learning Disability Awareness Trainer, he has delivered more than 100 training sessions to nurses, doctors and others in the medical profession. He was also invited to the House of Commons to give feedback about healthcare... a moment, he says, he is very proud of.

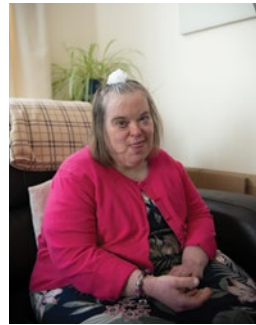
Photograph by Adam Hinton



Bridget Lynch

Bridget grew up as one of 10. She has the best sense of humour and is always full of mischief. Bridget loves art, colour and flowers. She paints and creates each day, and she loves country music and dancing. Bridget is very kind, thoughtful and loves to share everything with others.

Photograph by Richard Bailey



Emma Cooke

Emma likes taking long walks, drinking coffee and dancing. She loves spending time with her friends and eating good food. She is also the world's biggest fan of Tom and Jerry.

Photograph by Andrew Hamilton



Gary Wooler

Gary enjoys going out for lunch and to the cinema with friends. He loves music and television, and his favourite film is Dirty Dancing.

Photograph by Fiona Bailey



Chris Davies

Christopher grew up with his mum and dad and three sisters in South Wales. His hobbies include horse riding, snooker and disco dancing – especially to Shakin' Stevens. He enjoys working at a pottery / garden centre in Aberdare.

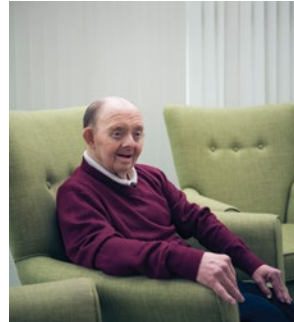
Photograph by Richard Bailey



David Wilding

David is a quiet cheeky man with a love of Dr Who and most soap operas. He is often the first on the dance floor and makes everyone smile.

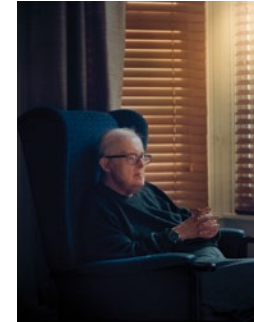
Photograph by Richard Bailey



George McCullagh

George grew up on a large farm in Northern Ireland. He has three sisters whom he is very close to. He enjoys listening to music, watching country and western movies, singing and painting. He absolutely loves dogs and can't resist giving them a cuddle when he sees them.

Photograph by Richard Bailey



George Wildgust

George was given a life expectancy of just 10 years when he was born, but he has certainly proved doctors wrong. He worked as a gardener before retiring and has always been very independent. He still loves to dance and sing karaoke, as well as draw and colour.

Photograph by Richard Bailey



Ian Forrest

Ian is the resident DJ in his community. He loves to keep up to date with the most recent music and helps DJ at all the parties. Ian is mad for Las Vegas and went for three weeks a couple of years ago. He has a paid job working at MacIntyre in their co-production and advocacy team.

Photograph by Richard Bailey



James Berriman

James lives with his wife Angela. He is a keen Manchester United football fan and enjoys meals out with his family and friends.

Photograph by Richard Bailey



Josie Berry

Josie lives in residential care and visits home once a month for weekends and loves Classic FM. She can tell you, despite her autism, which instruments are playing. She loves going to concerts and shows. Her reading and writing is good but not used much. She is a good swimmer and has medals and certificates.

Photograph by Richard Bailey



Julie Ann Lytle

Julie Ann lives in Northern Ireland in supported housing. She absolutely adores fashion, colour and make up. Julie Ann's favourite thing is dancing and in particular jiving.

Photograph by Richard Bailey



John Palmer

John played football in the 1989 Special Olympics in Leicester and is a keen Everton FC fan. He still lives independently, and held down a job at a local factory for more than 20 years. John loves a dance floor and enjoys showing off his ballroom and Latin moves.

Photograph by Richard Bailey



Jonathan Evason

Jonathan lives in Yorkshire and works as a foreman at Jennyruth Workshops, a charity and social enterprise set up by his parents. His proudest moment is being a torchbearer for the 2012 Paralympics. He was passed the torch by John Snow and then carried it from St Paul's Cathedral to Tower Bridge.

Photograph by Richard Bailey



Julie Thompson

Julie is a huge Star Trek fan and likes to watch re-runs of old series. She is a busy woman. She works four days a week at a wholefood shop, volunteers at a mother and baby group, and is also a parkrun marshal.

Photograph by Richard Bailey



Keith Fish

Keith is a very sociable man who enjoys being out every day. He loves attending the local team football and is always giving staff and his friends a Cliff Richard performance.

Photograph by Richard Bailey



Lee Blackburn

Lee is the resident movie critic amongst his friends, and his favourite activity is a trip to the cinema. He's a happy go lucky gentleman with a smile from ear to ear.

Photograph by Richard Bailey



Mark Ahrens

Mark has a zest for life that makes him the life and soul of the party. His sense of style is original - he's a real trend setter!

Photograph by Richard Bailey



Michelle Porter

Michelle is a beautiful person inside and out. She is gentle and shy. She loves a cuddle and completing her sewing. She has a close relationship with her mum, dad and two sisters.

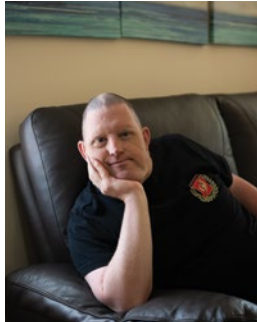
Photograph by Richard Bailey



Miriam & Billy George

Miriam is married to Steve and has a rescue dog called Billy George. She is a former netball player/coach, a huge Leicester City football fan, and a medal-winning Olympian, having competed alongside her husband as the only married couple in the Special Olympics in 2005.

Photograph by Clare Hewitt



Martin Baker

Described as 'The Boss!' Martin is always looking to help others and making sure everyone is ok. He is said to give the best hugs and makes a nice cuppa.

Photograph by Richard Bailey



Mary Hughes

Mary lives a very independent and busy life. She makes many of her own decisions about work and leisure pursuits and her passion over many years has been dancing, for which she has many trophies. She has lots of friends and enjoys going on trips to the theatre.

Photograph by Richard Bailey



Nicholas Crossley

Nicholas lives with his family. They have a herb garden at home and he attends Sheffield Organic Growers two days a week. Nicholas enjoys pricking out seedlings and cutting flowers. He has lots of friends there who he enjoys seeing each week.

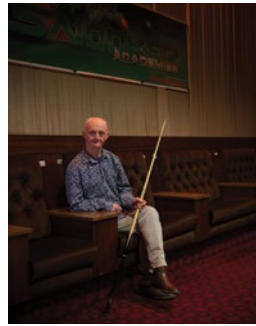
Photograph by Richard Bailey



Nicky Harris

Nicky is the resident artist amongst his community and has a love for superheroes. He is also football mad, supporting the mighty Tottenham Hotspur.

Photograph by Richard Bailey



Nigel Land

Nigel enjoys football and absolutely loves drinking tea. His favourite television programme is Tipping Point, and he is very close to his brother Bill.

Photograph by Richard Bailey

Paul Hughes

Paul lives with his sister Emma and her children. He goes to a day service five days a week where he helps out in technology workshops and volunteers at a food bank. Since the Coronavirus pandemic, he has become a TikTok sensation. Videos of Paul and his niece Maya have been viewed millions of times online. He says "I love being famous!"

Photograph by Richard Bailey

Rachel Somers

Rachel introduces herself as 'Blondie', a name she has given herself since going from a natural redhead to a blonde. She loves music and dancing and has a natural flair for art and design. She thrives on big hugs and cuddles, and her family mean the world to her.

Photograph by Richard Bailey

Sanjiv Malviya

Sanjiv is one of three siblings and he is incredibly close to his immediate and extended family. He takes great pride in his appearance and will insist on attending a barber for his monthly haircut. Sanjiv loves dancing and partying and is always the first and last on the dancefloor.

Photograph by Richard Bailey



Peter Wallace

Peter lived at home with his parents until he was 51. Since then, he has lived with support from Shared Lives South West. Peter loves filing and keeping his paperwork, photos and drawers in order. He also enjoys photography, swimming and drama. Peter loves to make people laugh.

Photograph by Richard Bailey

Rachel Silver

Rachel was born to be on the stage. Every day is a performance and her high kicks are to die for. Rachel is a natural carer who loves to help staff. Her favourite activity would be to go to a West End show.

Photograph by Richard Bailey

Sarah Morrish

Sarah is described as the most naturally warm person you could meet. She loves life and all activities associated, including the dentist! Sarah loves nothing more than an afternoon sat in the pub with a couple of beers.

Photograph by Richard Bailey

Susan Bunje

'Always look on the bright side of life' is how Susie lives her life to the full; whether it's enjoying sport, music, dancing and generally socialising, or in her roles as a sister, sister-in-law, and aunt, which are all very important to her. Susie is also immensely proud of her work; thirty years working in a children's nursery and now as a volunteer with the YMCA.

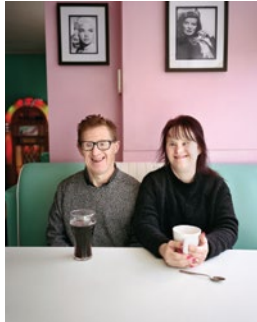
Photograph by Sian Davey



Susan Hanley

Susan is Senior Chair of Leep1, a self-advocacy organisation for people with learning disabilities in Leeds. She lives with her sister and family, and enjoys dogs, needlework, musicals and Midsomer Murders. She has dreams of becoming an MP and loves standing up for the rights of people with learning disabilities.

Photograph by Niall McDiarmid



Tommy & Maryanne Pilling

When Tommy and Maryanne married in 1995, they were thought to be the first couple with Down's syndrome in the UK to have got married. They met at a local training centre and their affection for each other soon grew. Tommy then produced a plastic ring which he had bought from a vending machine, and the couple were engaged. From that point on, they were inseparable. Sadly, Tommy died in the summer of 2020.

Photograph by Owen Harvey



Tina Pearcy

Cortina – or Tina as her friends and family call her – enjoys dancing, yoga, bowling and painting old furniture. Her parents were hotel managers so growing up, she learnt waitressing and housekeeping skills which she has carried through to her adult life. These days, she enjoys an active social life, including spending time with her boyfriend Clive.

Photograph by Susan Andrews



Tonda Peck

Tonda was born in Kuwait and lived there, California and Hong Kong when she was growing up. She now lives near the seaside in the UK with her husband Martin. They both love attending their drama group and performing in big shows at the Palace Theatre in Southend.

Photograph by Fiona Yaron Field



Richard Bailey (Photographer Biography)

Richard has been a freelance photographer for over twenty years, working primarily in the advertising, corporate and editorial sector. He is well known for his portraits of animals. These careful studies using studio lights and a backdrop, bring out a certain interaction and character in the animals. His images have featured in many photography books, he has exhibited widely and won numerous awards, but his real passion is Shifting Perspectives, which he has been curating for the last fifteen years. Shifting Perspectives is an internationally touring photographic exhibition, which is concerned with all aspects of Down's syndrome. He is represented by Mark Gibson Photography in the UK and alongside his commercial work Richard is always working on personal projects.



Blair Moore (Photographer Biography)

Blair is a dance artist, filmmaker and photographer based in the UK. Blair's projects range from dance short films, dance trailers, documentaries and more. Blair is interested in telling other people's stories in the form of dance, film and photography. Blair has been fortunate enough to have worked on film/ photo projects with companies such as Rambert Grades, Hofesh Shechter, National Youth Dance Company, Toussaint to Move and most recently Rhythmflow. Blair is the founder and director of Blair Moore Media.



Aron Hoise (Photographer Biography)

Brought up in the Devon town of Totnes, Aron's love of the image developed over his childhood years watching old classic Cary Grant or Elvis movies and flicking through the fashion magazines that were always lying around the house.

Photography however, was something that came much later in life. After following paths into carpentry, cabinet making, a degree in furniture design and finally ending up in a family retail business, it wasn't until 2006 that Aron picked up his first camera in earnest.

"Having made a business decision to start an online shop for our stores, I decided to try my hand at producing the product shots. It was a lot of trial and error for many years but slowly things started to sink in. I remember reading someone saying it takes about 10,000 reasonable shots to start to get to grips with the craft of photography. I'm probably coming up to that number and yes I'm starting to feel a bit more confident about how it works. Photography, at the highest level, really is a complex craft of technical know-how and creative direction. You've then got to add into that the story telling element and the characters of people within your image. It's a lot of things to line up. But that's the beauty of the craft."

Additional project photographers

Andrew Hamilton / Adam Hinton / Clare Hewitt / Edna Bowe / Fiona Bailey / Fiona Yaron Field / Laura Pannack / Niall McDiarmid / Owen Harvey / Sian Davey / Susan Andrews

The Next Generation

by Blair Moore

Fifty years ago being born with Down's syndrome was a very different story. Families were very much left in the dark and uneducated about the prognosis and what life would be like. But that was then. Advances in medicine, technology, attitudes and opportunities mean that story has been, and continues to be rewritten.

This series of portraits were shot here at Normansfield Theatre.

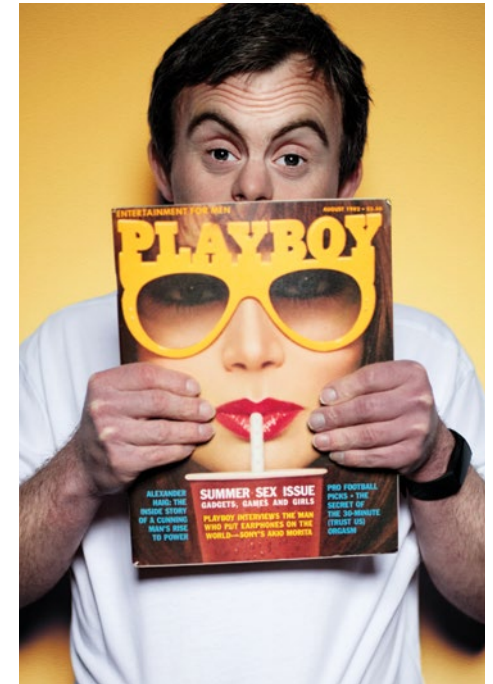


Breaking Boundaries

by Aron Hosie

I was very honoured to be asked to create a series of images for this exhibition. The idea was to inject a dose of glamour, a provocative edge and a nod to the worlds of fashion and Hollywood into the photos. The result hopefully, is a set of images that put a smile on your face and raise an eyebrow at the same time. Possibly even raise a question or two.

We live in a time where inclusivity is at the forefront of social thinking, where old ideas and stigmas are slowly being torn apart around race, ethnicity and minority groups. I like the idea of challenging how we see Down's syndrome and trying to push those boundaries.



Connected

March 2020 when lockdown began families, friends and communities were suddenly isolated from one another. We were no longer connected to our routines, everything stopped and we faced a new reality. All of the important forms of human contact we grow to rely on suddenly couldn't exist. After many months in isolation regular contact and connections slowly returned. We began to feel better together.

This collection of photographs have been submitted by friends, family, members and associates of the Down's Syndrome Association.



2020

2020, and the year that followed, was something nobody ever could have imagined. It was a frightening and uncertain time as the World adapted to keeping everyone safe. And whilst the reality of what was happening around us was bleak, the courage, creativity and capacity to adapt to the new normal inspired some incredible stories.

This collection shares just some of those stories. Many more can be found on our website and social media channels.



"Face Masks" by Will Shepherd

Oral Histories



Adam Veness

Adam lives with his wife Cathy of 25 years, in a supported housing community. Adam worked for the Post Office for 27 years and before the pandemic, was volunteering regularly with the British Heart Foundation. Adam describes his biggest achievement as becoming a husband, and recalls how his life changed forever when he met Cathy 30 years ago.



Alan Hicks

Alan lives with his mum and works in the café at Leep1. He dreams of being an actor. Alan is proud to have Down's syndrome and views his work as a Steward for the People's Parliament as vital for getting the voices of people with learning disabilities heard.



Anya Souza

Anya lives in London with Paul, her partner of 35 years. Anya has been a Trustee of the Down's Syndrome Association for more than 25 years. She feels passionately about fighting for the rights of people who have Down's syndrome and keeping them up to date with issues that impact their lives.



Julie Thompson

Julie is a huge Star Trek fan and likes to watch re-runs of old series. She is a busy woman. She works four days a week at a wholefood shop, volunteers at a mother and baby group, and is also a parkrun marshal.



Miriam Lyne

Miriam is married to Steve and has a rescue dog called Billy George. She is a former netball player/coach, a huge Leicester City football fan, and a medal-winning Olympian, having competed alongside her husband as the only married couple in the Special Olympics in 2005.



Richard Morgans

Richard is a self-confessed Thespian, having appeared in a number of productions over the years. Richard lives independently with his flatmate, and is very close to his family. He leads a very busy life, and is currently writing a play. He's also a huge Star Wars fan.



Cathy Veness

Cathy lives with her husband Adam. She has happy memories of growing up and remembers learning creative and practical skills at Brownies and the Girl Guides. Cathy volunteers at her local church and also a children's nursery. Cathy and Adam have been happily married for 25 years.



Emma Merrick

Emma lives in her own flat in a supported tenancy. She has worked as a kitchen assistant at a school in Leicester since 2012 and before that, she was a kitchen assistant at a care home for almost 20 years. Emma loves being with her sisters, playing board games, pool, table football and darts - especially when she wins!



Jonathan Evason

Jonathan lives in Yorkshire and works as a foreman at Jennyruth Workshops, a charity and social enterprise set up by his parents. His proudest moment is being a torchbearer for the 2012 Olympics. He was passed the torch by Jon Snow and then carried it from St Paul's Cathedral to Tower Bridge.



Roger Quemby

Roger has happy memories of cycle touring with his parents growing up, and he was also a Cub Scout where he gained his Gold Arrow Award. In the Scouts, he took up canoeing which he still enjoys. Work experience brought Roger employment with People First, travelling alone in London to meetings. He now volunteers representing patients on NHS committees, as well as supporting adults with learning difficulties at speaking up groups and assisting at a weekly disco.



Susan Hanley

Susan is Senior Chair of Leep1, a self-advocacy organisation for people with learning disabilities in Leeds. She lives with her sister and family, and enjoys dogs, needlework, musicals and Midsomer Murders. She has dreams of becoming an MP, and loves standing up for the rights of people with learning disabilities.



Tina Percy

Cortina - or Tina as her friends and family call her - enjoys dancing, yoga, bowling and painting old furniture. Her parents were hotel managers so growing up, she learnt waitressing and housekeeping skills which she has carried through to her adult life. These days, she enjoys an active social life, including spending time with her boyfriend Clive.

We would like to say a huge thank you to all the wonderful people who sat for portraits or shared their story for this exhibition. We are also very grateful to all their families, friends, colleagues and support workers who helped to make their participation possible.

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