



**Changing
Our Lives**

**Annual Report
2020-2021**

Foreword

A year like no other!

This year's work took place in unprecedented times. Amidst a global pandemic, we found ourselves adapting our work so that we were able to continue to serve a community of disabled people and people with lived experience of mental health difficulties, many of whom were shielding for the entire year. Like people across the country, our homes became our workplace and our days were filled with calls and meetings over Microsoft Teams and Zoom. Some of our most rewarding work, however, occurred as a result of the pandemic pushing us to find new and creative ways to connect and work with people. We made window visits, taking Covid lockdown parcels and presents to people who could not get out, and developed projects such as *Speakeasy* which brought people together via online via music events.

While the world was bemoaning the forced isolation of Covid-19 restrictions, disabled people told us that isolation and loneliness were often their norm, and although the pandemic had made life harder, lots of what they were experiencing was not that far from their everyday experiences pre-Covid. Three projects highlighted in this annual report illustrate this disparity between the ordinary, everyday experiences of the vast majority of the general public and the lives disabled people often find themselves living.

The *Common Ground* campaign and *What I wish people knew about autism* project both used the arts to enable individuals to express their thoughts and feelings about their lives, combat stigma around loneliness and encouraged people to question perceptions around disability. Taking shape across social media and online art exhibitions, their messages remained powerful despite pandemic limitations. At the other end of the scale, the Hospital to Home project charted the life stories of people who, after years of being trapped in assessment and treatment units, are now thriving in their own homes, enjoying freedoms previously denied to them within the confinements of the hospital setting, the regulations of which make Covid-19 lockdown restrictions look mild by comparison.

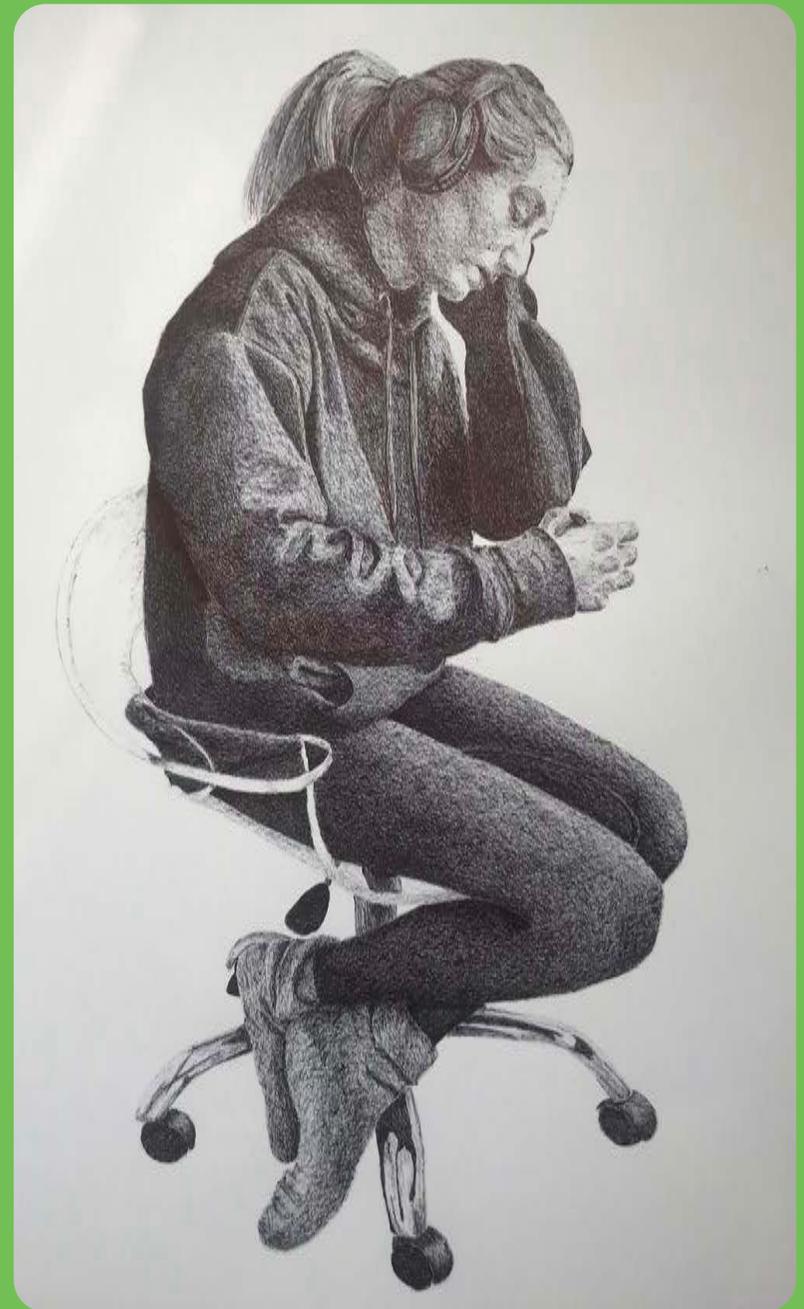
In light of the pandemic, health inequalities, which are always a focus of our local and national work, also became even more severe for many people we work with. At a local level in Sandwell, our *Quality of Life* programme worked with people with learning disabilities who lived in their own tenancies and explored how social care providers enabled them to maintain good health and wellbeing, while *The State of Sandwell* focused on people from minority ethnic communities and their experiences of mental wellbeing during the pandemic.

At a national level, we were commissioned by NHSE to highlight the successes of learning disability nursing across England. Working alongside learning disability nurses, people with learning disabilities and their families, we gathered examples of where health inequalities had been successfully tackled and overcome across the NHS Trusts, and real life stories of the positive impact learning disability nursing had brought about in people's lives; these collaborations yielded two publications of best practice which were then shared at an NHS Symposium in the winter of 2020. Across the year, we also worked with families and disabled people from around England on the *Got My Back* project, recording their testimonies of how effective, personalised postural care is essential to unlocking a good quality of life. At the same time, we also worked with families and disabled young people to develop a digital postural care passport, which will be launched later in 2021. In all of this work, there was a resounding consensus from people that health inequalities and mental wellbeing had been significantly negatively impacted due to the pandemic.

Although the year posed many challenges, it pushed us to find new solutions and develop creative new ways of tackling issues. These new approaches are now embedded in our work moving forward and will surely benefit us in the long run.

Jayne Leeson MBE

CEO



About us

Changing Our Lives works in coproduction with disabled people and people with lived experience of mental health difficulties of all ages to find solutions to social injustice and health inequality.

An ordinary life

All of our work is rooted in the belief that no one is too disabled and no one's mental health is too complex to lead an 'ordinary life'. Whatever our area of work, the drive for people to lead ordinary lives is at the heart of our approach.

Social model of disability

Our approach rests firmly on the social model of disability where the person is disabled by society and the way it is organised, as opposed to the medical model which believes the person is disabled by their condition and is seen as a problem to be fixed. As such, we don't believe people's lives should be limited or defined by labels and diagnoses and are committed to reframing how society views mental health and disability.

Human rights

Human rights are at the cornerstone of our democracy and enable us all to live well in communities that value the equal dignity of each person. They are the freedoms and protections that every person has simply because they are human. We approach all of our work with a belief and understanding that human rights are a basic set of rights and freedoms that we are all entitled to. As human beings we do not have to qualify for human rights; we are born with them. This includes us all, whether disabled or not.

Recovery Model

We are committed to the recovery model in mental health. Just as we all have physical health, so we have mental health. This model does not focus on symptoms and conditions but champions:

- building resilience of people
- supporting self-development and self-esteem
- a strength-based approach
- a personalised approach and aims for each individual to gain more control over their life
- social recovery' where relationships and community connections are strengthened
- a journey, not a destination
- building a meaningful life, as defined by the person themselves

Coproduction leading to paid work

Changing Our Lives is committed to ensuring that disabled people are paid for the co-produced work they carry out across the organisation.

In 2020 to 2021, we paid 15 disabled people for a range of work, which included being part of the State of Sandwell advisory group, playing leading roles in the Quality of Life programme, producing an awareness raising film around autism, and being part of a reference group for a joint project with the University of Birmingham looking at why people with learning disabilities and autistic people find themselves stuck in locked hospitals.

Some of these individuals are Associates of the organisation, while others are individuals who may work with us on a one-off basis but nevertheless contribute their skills and expertise.

We also paid family members to work with us on the development of the digital postural care passport, as their 24/7 commitment to facilitating postural care for their sons and daughters put them in a unique position to shape and guide this work moving forwards.



**No one is *too disabled*,
or *too affected* by
mental health difficulties,
to live an *ordinary life***

“Research conducted prior to the pandemic [shows] that whilst many people with learning disabilities are highly motivated to use technology, they are often unable to effectively or meaningfully do so. [...] Several researchers have argued that a major reason that people with learning disabilities are excluded from the benefits that using technology can offer them is that supporters (e.g. parents, carers and other professionals) are often unable or unwilling to facilitate access and support sustained use of technology.”

Seale, 2014; Sorbring, Molin & Löfgren Mårtenson, 2017).
Keeping Connected and Staying Well, The Open University
2020

In 2017, 56% of adult internet non-users were disabled, much higher than the proportion of disabled adults in the UK population as a whole, which in 2016 to 2017 was estimated to be 22%. For internet non-users aged between 16 and 24 years, 60% were disabled in 2017, a proportion that is the same as for those aged 75 years and older.

ONS, 2019



In 2020, Changing Our Lives began work on our Speakeasy project in Sandwell, which aims to build social connections and promote digital inclusion for people with learning disabilities, autistic people and their families. The Covid-19 pandemic has magnified the isolation and digital exclusion that people with learning disabilities and autistic people experience in their everyday lives. With the majority of the community shut and many people being told to shield, people's lives have been completely disrupted. ONS data found three in four people (74.6 per cent) with a learning disability believe their wellbeing has been affected by the impact of coronavirus, compared with 37 per cent of non-disabled people (ONS, 2021).

Using Zoom, we have facilitated a series of virtual "Speakeasies". Each Speakeasy is totally unique and to date we have hosted a variety of virtual get-togethers including a Christmas Cabaret, Valentine's Cabaret, Pub Quiz, Pamper Night and Drag Bingo. Each person that attends has a personalised "Speakeasy Parcel" delivered to their doorstep to add to the atmosphere of the night.

This may be their favourite food or drink. Amongst the fun and entertainment, people chat and share their stories. Some of these stories have been captured through song and we will be developing an album of these songs as part of the project.

We have supported people with developing their digital skills to take part in Speakeasy nights and in some cases are supporting people to use Zoom for the first time through 1:1 support. Additionally, we have developed a tablet loan scheme, through which a number of tablets are available to those who don't have the required technology to take part in the project.

We have connected old friends, who in some cases are seeing each other for the first time since lockdown began. We have also brought people together who would otherwise not have known each other. Friendships and community connections are being established and as time progresses these will develop naturally outside of the project.

"It was just great as I haven't seen her since about 12 months ago. And it was fantastic that I actually saw her."

"I loved the care, the humour and the sense of community that came across even through the Zoom format."



"I love meeting new people. It's nice to get to know them better on Zoom."

"Huge thank you to Changing Our Lives for a brilliant night and for fantastic Christmas gifts for Dave. Amazing band, fab Fizzogs, great Drag Artist."

"I really enjoyed the cabaret. It was fun. I really enjoyed the dancing and singing."



"Because you are vulnerable you are not disposable, you are not any less valuable, and you are not any less deserving. This pandemic has taught the world a lot of what it's like to live with some conditions, but only the small part of it. Being able to deal with things and carry on as the vulnerable people in this world do, is amazing, it takes courage and strength to fight everyday just for a tomorrow."

Common Ground

"If someone shares their story it might make others reach out and share theirs too and this way, the more people share, the more they feel connected and the more future connections and support they create for others."

Community Connecting

Since 2017, we have been working with the Co-op Foundation on Common Ground, which uses 'Community Connecting' as an approach to tackle youth loneliness and build connections between young disabled people and their local community. Too often the social isolation and loneliness that young disabled people experience is defined by their disability, which can be all the more isolating. For 2019 - 2021 our aim was to continue to build on what we've learnt so far, developing a range of works to connect and motivate young people to start a conversation around youth loneliness.



Human Rights training

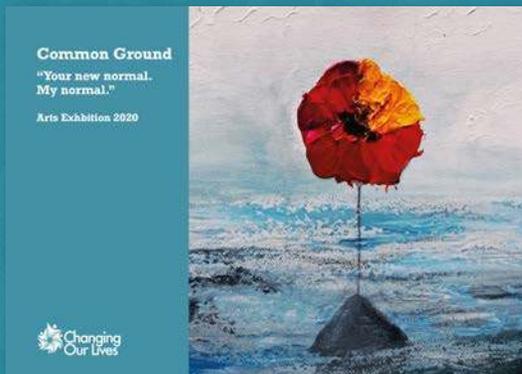
Between 2019 - 2021, Changing Our Lives partnered with the Law School from the University of Birmingham (UoB) to design and develop a bespoke Human Rights training session aimed at young people in Wolverhampton.

In 2019, 27 pupils from mainstream schools took part in face-to-face training that was created and delivered by 6 UoB students alongside Changing Our Lives staff and 2 young disabled people from the city of Wolverhampton. In light of the Covid-19 pandemic, in 2020 a virtual form of this training was developed by UoB law students with support from the Changing Our Lives team. In 2021, this online session was delivered by UoB students alongside Changing Our Lives staff to young members from youth forums facilitated by the City of Wolverhampton Council.

"Your new normal. My normal." social media campaign

Throughout the course of the Covid-19 pandemic, people from all walks of life have expressed their feelings of loneliness and isolation, donning the phrase "the new normal". However, for some young people, these feelings of loneliness are the everyday normal. We sought to raise awareness of this by capturing the stories of young disabled people and their non-disabled peers through the arts. Changing Our Lives use the arts as a vehicle to highlight and challenge societal prejudices and perceptions. By creatively opening up the conversation on youth loneliness, we wanted young people to feel powerful and confident to share their stories.

The range of artworks featured on our social media channels throughout the course of the campaign. The campaign also resulted in an online exhibition with [Wolverhampton Art Gallery](#), featuring the original artworks of young people whose work was selected by a judging panel.



To view the full collection of artwork produced for the "Your New Normal. My normal." campaign, [click here](#).



What I wish people knew about autism...

Promise 1: Sandwell Autism Strategy

Living an ordinary life is often challenging for autistic people because of systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently). Misunderstandings and judgmental attitudes based on misinformed stereotypes creates an unwelcoming community and can be one of the biggest barriers to autistic people living life the way they want. More needs to be done to tackle them which is why the first promise of the Sandwell Autism Strategy, which Changing Our Lives coproduced with autistic people in 2019.

A better understanding of autism would improve every part of autistic people's lives, increasing the chances of an early diagnosis and appropriate support, lowering incidents of bullying at school and in society, making communities more welcoming and accepting, and improving employment opportunities.

"I am accepted as who I am within my local community. People and organisations in my community have opportunities to raise their awareness and acceptance of autism."



Autistic people themselves are in the best position to inform and educate non-autistic people about autism, which is why Changing Our Lives ran the “What I wish people knew about autism...” project during the pandemic. This project was about autistic people themselves using their own experiences and creativity to produce pieces of art to encourage more awareness, understanding and acceptance of autism in Sandwell.

Autistic people were invited to create pieces of art work using any medium around the themes of:

- My world – exploring ways in which autistic people can experience the world differently to non-autistic people
- Acceptance and respect – exploring issues around respect and acceptance of neurodiversity
- Change – exploring what the neurotypical world needs to do to become more inclusive of autistic people

Contributors were free to create work that was celebratory, highlighting the gifts, talents and strengths that can come with autism; or challenging, focussing on the barriers, struggles and difficulties that autistic people face; or to simply express their day to day experience living in a world not built for autistic people.

There were some very powerful, insightful and expressive submissions and three pieces were chosen for a prize.



AUTISM ACCEPTANCE IS REALISING I AM A NORMAL VERSION OF ME - JACK WHITEHOUSE



A Springboard to Tackling Health Inequalities in Sandwell

Challenging the injustice of health inequalities has always been a high priority for Changing Our Lives. Having good health is fundamental to living an ordinary life.

The disturbing levels of health inequalities experienced by people with a learning disability and autistic people have been well documented in the last twenty years: people with a learning disability and autistic people have poorer health and die earlier than the general population. Shockingly, many of these deaths could be prevented by public health interventions or better access to high quality care.

The COVID-19 pandemic has amplified the everyday discrimination experienced by people with a learning disability, including around health inequalities. In February 2021 Mencap reported that Covid-19 accounted for 80% of deaths of people with a learning disability in the week ending 22 January, a disproportionately high number compared to the general population in England and Wales, where 45% of deaths were COVID related.

With these alarming statistics in mind, Changing Our Lives worked with Sandwell Council to plan and carry out a Quality of Life Review to explore how well people in supported living are supported to maintain good health and wellbeing in general, and throughout the pandemic.

The Health Charter for Social Care Providers 2017 (the Health Charter) was used as a basis for the review. This charter was developed with people with learning disabilities and their families and aims to support social care providers to improve the overall health and wellbeing of people with learning disabilities. The review took place over a six-month period and involved 9 social care providers; the review team spoke to 82 people overall, including people with a learning disability, managers, support staff and family members.

In general, the review team found that the support people get to maintain their health and wellbeing is good enough and there were some great examples of innovative and creative practice. However, there was also evidence of shortcomings in practice in some areas and an inconsistent awareness and understanding of health inequalities and people's rights.

The findings and recommendations from this review will be presented to Sandwell Health and Wellbeing Board in June 2021 where strategic backing will be sought to take forward key actions and developments. Changing Our Lives will host a Health Inequalities Conference in the autumn aimed at providers to raise awareness and understanding of key health inequalities and secure sign up to the Health Charter and begin to close the health inequalities gap in Sandwell.

State of Sandwell

Building upon the findings of the State of Sandwell 2019, in 2020 Changing Our Lives set out to have conversations with Sandwell residents about their mental health. This year, the focus was the impact of COVID-19 on the mental health of people from minority ethnic communities in Sandwell. At the time of designing the research methodology, evidence was emerging to suggest that COVID-19 was having a disproportionate impact on some minority ethnic communities in the UK and that the pandemic was linked to various social and economic outcomes that were likely to have a negative impact on people's mental health.

Reaching people by videoconferencing and phone calls, Changing Our Lives spoke to Sandwell residents from Black and Asian backgrounds. Many of these people had additional risk factors of disadvantage from COVID-19 including disabled people, women (including those with caring responsibilities)

and frontline workers. After the conversations, a core group of residents who had participated came back to analyse the data with Changing Our Lives staff and identify key themes.

As with the State of Sandwell 2019, people spoke about their mental health as being interwoven with all other aspects of their everyday lives and described positive, self-directed activities as important for maintaining their mental health and wellbeing. Cultural identity and heritage was identified as an important factor for many people in how they understood their own mental health, but this was deeply personal and individual, and blanket assumptions about ethnicity or culture were seen as particularly unhelpful.

In 2021, Changing Our Lives will present the findings from this work to a range of relevant stakeholders and will coproduce an action plan that will inform the work of the Mental Health People's Parliament.

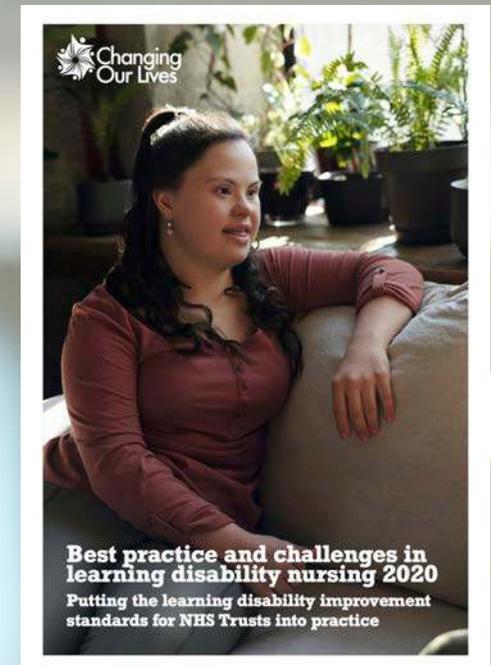


Best practice in Learning Disability Nursing and Resetting the Narrative

In December 2020 Changing Our Lives published two books about learning disability nursing. 'Best practice and challenges in learning disability nursing' was commissioned by NHS England and Improvement, and illustrated how nurses in a variety of settings had put the 'Learning Disability Improvement Standards for NHS Trusts' into practice. 'Resetting the Narrative' was commissioned by Health Education England and told the stories of people with learning disabilities, autistic people and their families reflecting on the importance of Learning Disability Nurses in their own lives. The stories spanned more than 20 NHS Trusts, a learning disabilities regional network and a handful of voluntary sector organisations and they demonstrated the creativity, tenacity and warmth that are the hallmarks of great learning disability nursing.

Changing Our Lives presented the two books at The 2nd National Learning Disability Nursing Symposium, sharing some of the stories featured. After the Symposium, connections were forged between the Trusts mentioned and other delegates over Twitter, including Respiratory Charge Nurse Justin Wyatt who was invited to speak to Learning Disability Students at Teesside University about his innovative pathway for patients with the label of profound and multiple learning disabilities (PMLD).

Changing Our Lives is continuing to work with some of the NHS Trusts on some social media spotlights around particular pieces of best practice, and many of the individual people, families and nurses that were featured in 'Resetting the Narrative' have returned in 2021 to collaborate with us on awareness raising or our new digital inclusion work, and some are also undertaking paid roles on one of our national research projects.



Got My Back: Young people and families putting themselves in control of postural care

Changing Our Lives has a long history of working with disabled people to raise awareness of health inequalities, challenge the systems that perpetuate them and remove barriers to healthcare. Our vision is that no-one is too disabled to live an ordinary life, and this includes having equal access to good health outcomes.

A healthy posture is important for us all, but for people with reduced mobility, it is more difficult to maintain a healthy posture. This means that over time, some people develop body shape distortions. These changes are not inevitable. Postural care is any intervention which protects a person's body shape and reduces their risk of health complications associated with distortion.

In 2019, NHS England and Improvement commissioned Changing Our Lives to write the stories of 6 people who demonstrate the benefits of good postural care. We worked with young people and family carers to build a picture of their experiences with postural care. Despite being of critical importance to a person's physical health outcomes, what really shone out of the 6 stories we gathered was the way that good postural care acts as the cornerstone of a full, connected and ordinary life. Whether scaling a climbing wall, visiting the beach with family or taking those first strides into independence as a young adult, maintaining a healthy body shape freed people up to achieve what they wanted to.

However, a theme throughout all the stories was a need for more information and awareness among people, families and healthcare professionals. Localised pockets of great practice work for those people who are lucky enough to come across them, but a consistent level of understanding and access to postural care is needed wherever disabled people are. Changing Our Lives will share the 'Got My Back' stories in Summer 2021 and will use them as a springboard for our upcoming Postural Care Twitter Chats and for a learning and sharing event in September 2021 aimed at learning disability nurses.



Digital Postural Care Passport

“Our vision is of a world where people’s body shape is protected, so that we can enjoy our lives free from pain, exercising our basic human rights and living our lives to the full.”

Changing Our Lives, 2018

This is the vision from our postural care strategy which was written in coproduction with disabled people, family members, healthcare professionals, academics and equipment providers in 2018.

In 2020, Changing Our Lives was commissioned by NHSE to produce and pilot a digital passport for young people with the label of profound and multiple learning disabilities. The passport focuses on communication and postural care and is a way of families sharing the knowledge and expertise they have about their child or young person with others who may work with them.

“Postural care is everything to us as a family. If my son is not supported to have good posture then everything else fails – he can’t stand in his standing frame if he’s not in a good position, he can’t sit in his wheelchair if he is not comfortable. He can’t have a good quality of life.”

Changing Our Lives, 2018

Changing Our Lives has worked in coproduction with family carers and experts in the field of postural care to produce the draft passport. The passport is accompanied by a series of short films created by Sarah Clayton (Simple Stuff Works) and Sharon Sutherland (www.posturedmobility.com), which will help families to consider what to include in the postural care sections of the passport.

At the time of writing, the passport is being piloted by families at a local special school in Staffordshire. Their input and expertise will shape the final passport. The long term aim is that the passport will be freely available via our website and will result in outcomes for those with communication and postural care needs across the country. We aim to establish a network of family carers who will champion the passport through their networks.

Hospital to Home

Over 20 years since the Human Rights Act became law in the UK and nearly 10 years since the shocking human rights violations at Winterbourne View hit the headlines, pledges to make sure that people with a learning disability and autistic people were no longer locked away in inpatient units have still not materialised. Alarming, there are still around 2000 people with a learning disability and autistic people currently stuck in inpatient units, being denied a life in the community. Changing Our Lives has a strong and proud history of working with people who find themselves stripped of the most basic human rights, often those people with a learning disability and/or autistic people in inpatient units.

Our work is shaped by a recognition that people themselves are in the best position to know what works for them. So, in 2020 we published 'From Hospital to Home' a collection of stories that describes three people's unique journey from inpatient units to ordinary lives in the community. The stories honour the courage of each person and celebrate their achievements. They highlight the essence of what has helped them along the way and show what is possible when people are put centre stage of their own lives. Their real experiences show first hand that no one is too disabled or too affected by mental health difficulties to live an ordinary life.

Since publishing the stories, one person from the book has gone on to move out of his flat in a shared building, to his new home with a new provider where he will be taking on even more independence and control over his own life. Another person from the book is working with Changing Our Lives on research that aims to identify and challenge the barriers that other autistic people and people with learning disabilities face on their journeys from hospital to home.





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Changing Our Lives

Tel: 0300 302 0770

Email: ask@changingourlives.org

Web: www.changingourlives.org

Twitter: [@positive_lives](https://twitter.com/positive_lives)

Registered Charity Number: 1093883