



Changing  
Our Lives



**Annual Report 2020-2021**

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## Foreword

A year away from our 20th anniversary, this past year has been a time of reflection where I have considered our work in the light of the past 20 years. Having founded the organisation in 2002 with a group of colleagues with learning disabilities, our work has without doubt changed over the years in response to people's situations, and to the political and social climate. Over this time we have developed and refined our practice based on what we know works. However, what has not changed are our values, and our fundamental commitment to person centred ways of working, and to coproduction at an individual, community and strategic level, which remain as strong today as they were in 2002.

The annual report describes a range of our work from 2021-2022, including projects which showcase what is possible in people's lives (the Ordinary Lives and Hospital to Home book launches), projects which systematically gather evidence to measure and improve quality of life (200 Lives, Why are we stuck in hospital?), alongside projects which take a long term approach to challenging and overcoming injustice (person centred planning and advocacy) through to practical, projects that make a relatively immediate impact on a person's quality of life (Digital Life Lines, Common Ground and the FitBit project). Having a range of work is not only what people we work with want, but it is equally important when tackling social injustice and health inequalities, as the team thrives on this variety. When faced with achieving positive outcomes in the face of the systemic discrimination and disadvantages, having variety keeps the team fresh, motivated and resilient.

Jayne Leeson MBE  
CEO

# Who we are

Changing Our Lives works with people with a learning disability and autistic people, as well as people with lived experience of mental health difficulties of all ages. However, in many of our projects we chose to target three specific groups of people who find themselves particularly disadvantaged:

People with the label of profound and multiple learning disabilities

People from minority ethnic communities

People who are trapped within the locked hospital system

The Got My Back postural care work particularly focuses on people with the label of profound and multiple learning disabilities; our person centred planning and advocacy and the two research projects, 'Why are we stuck in hospital' and '200 Lives' focus on people trapped in locked hospital settings, and Beyond the Stigma and Equal Treatment focus on people from minority ethnic communities. Focusing some of our work on these specific groups is important to us, and the team has honed its skills and experience over the years so we can work alongside these individuals to bring about positive change in their lives.

Since we were established in 2002 we have adopted a coproduced approach, working in partnership with disabled people and people with lived experience of mental health difficulties to shape and deliver projects. In 2021-2022 we continue to be committed to this approach.

We paid 12 disabled people which included 5 people with physical disabilities, 4 autistic people, and 3 people with learning disabilities and one individual with lived experience of mental health difficulties. 33% of these individuals came from minority ethnic communities. We also paid two family carers for their work with us. Creating paid opportunities for disabled people is something we have done since the charity was established in 2002 because we know that working with and investing in people close to the issue is the best way to bring about meaningful and sustained outcomes.

## Our vision and values

### Vision

Our vision is of a society in which disabled people and people with lived experience of mental health difficulties of all ages are afforded universal human rights, resulting in them being in control of their own lives as equal citizens.

### 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. An ordinary life, first coined by the King's Fund in their seminal report *An Ordinary Life* (Kings Fund 1980), promoted the concept that people with learning disabilities should live in ordinary houses, in ordinary streets and be part of ordinary communities.

## Social model of disability

Our values are rooted in the social model of disability, which guides our approach. The social model of disability recognises that the person is disabled by society and the way it is organised, as opposed to the medical model which views the person as disabled by their condition and therefore 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.

## 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
- the journey, not the destination
- building a meaningful life, as defined by the person themselves

## References:

Kings Fund. (1980). *An Ordinary Life: Comprehensive locally based residential services for mentally handicapped people*, London: Kings Fund.

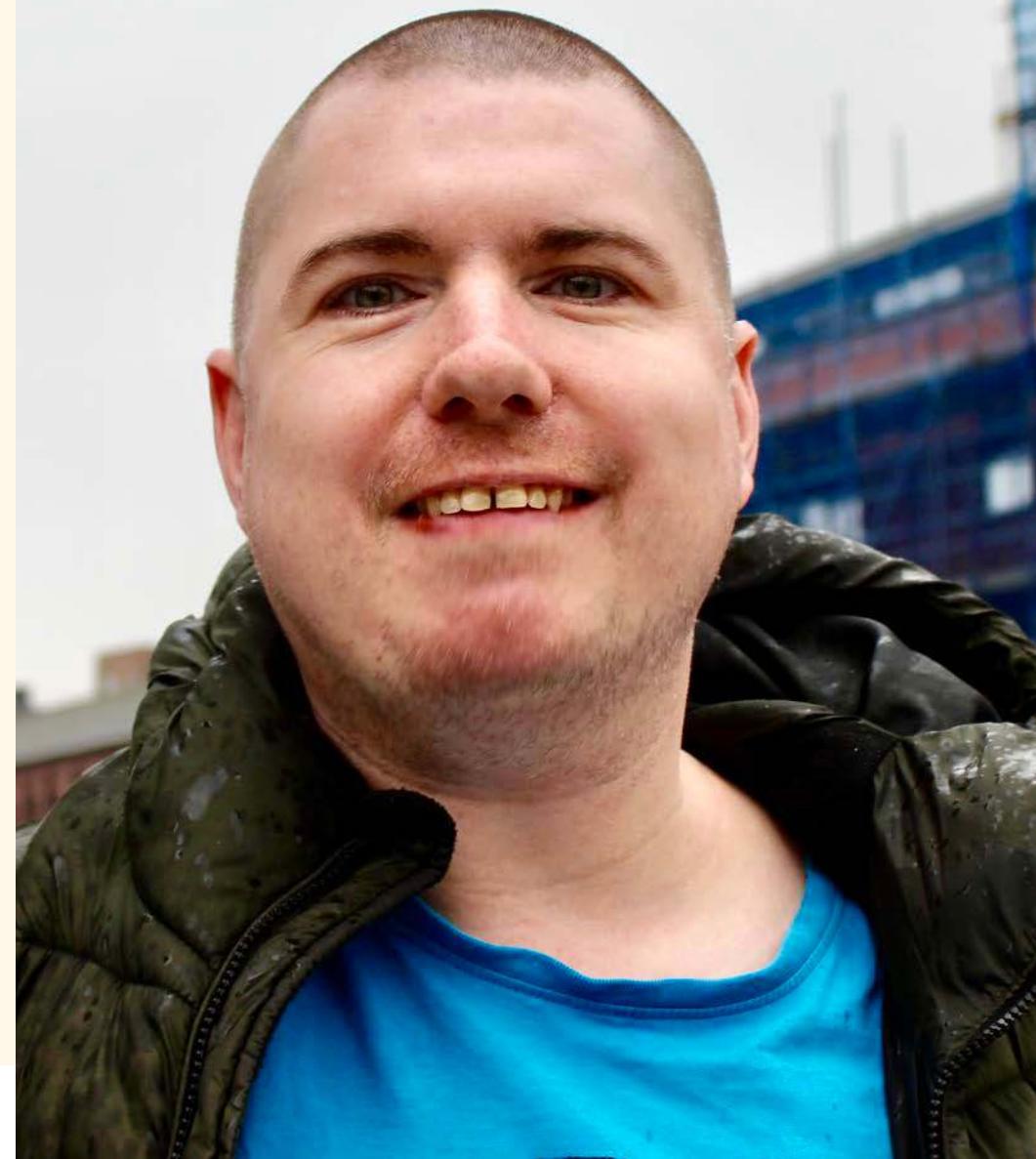


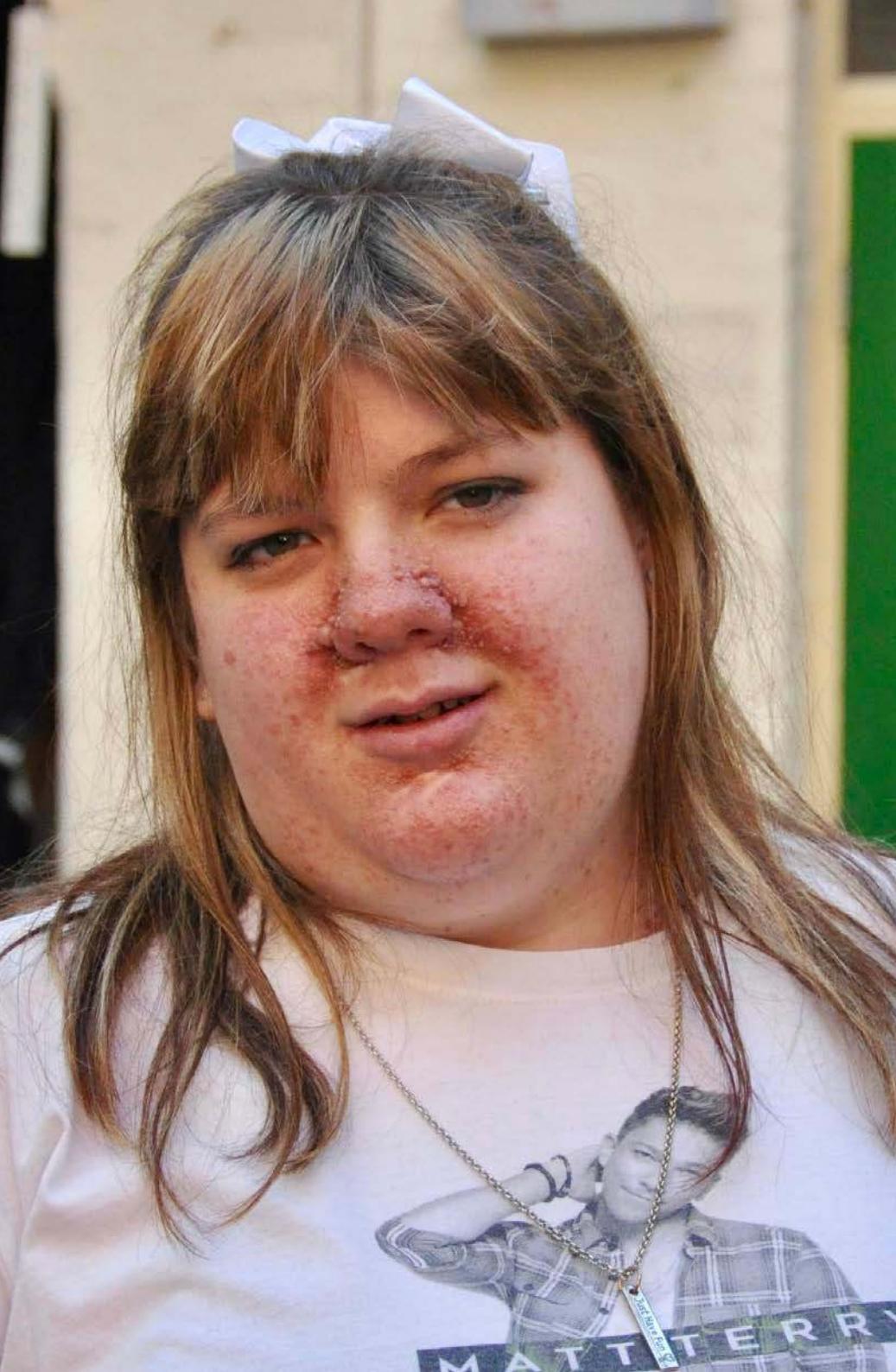
## Person centred planning and advocacy

Changing Our Lives has a strong and proud history of working with people who find themselves stripped of the most basic human rights, including those people with a learning disability and/or autistic people trapped in inpatient units. Tackling this injustice is a priority for Changing Our Lives; one of the ways we do this is through future planning with individuals who are in inpatient units. This work is vital in not only achieving better, ordinary life outcomes for people but also in our drive to change the wider narrative towards the belief that no-one is too disabled and no one's mental health is too complex to lead an 'ordinary life'.

Our approach to future planning is bespoke to each individual, and includes a combination of person centred planning, advocacy and coproduction with the person and family around individualised support/service design. Our work is always shaped by a recognition that people themselves are in the best position to know what works for them, so we spend time with the person and those that know them well. We coproduce a person centred plan with individuals, we use the tools of advocacy to move them closer to the future they want and we ensure that they are at the centre of designing their own journey out of hospital and the support they need to live a full life in the community.

The following are some of the examples of outcomes people have achieved through this work.





## H

H has had several hospital admissions over the years. H was doing really well just 8 months ago and was at the point of moving out of hospital back into the community. However, due to the hospital closure, H was suddenly and without any warning or planning moved to another hospital. Unsurprisingly, H found this difficult to cope with, and reacted in the only way they knew how by lashing out at staff, being verbally abusive and breaking things. Within weeks H found themselves in long term segregation. H is now out of long term segregation and going out into the community.

We have:

- Challenged the hospital team to find ways to support H positively and move out of long term segregation.
- Linked in with H's community nurse who has a good relationship with them so that we could visit jointly and begin to form a relationship, as H finds it difficult to form relationships with new people.
- Used our links with commissioners to ensure that concerns about the way H was being supported were addressed quickly and at the appropriate level.
- Challenged the hospital team to reduce the time H is expected to go without incident before community leave is allowed to make it achievable for them.

## M

M had lived in hospital for approximately 15 years. M is autistic and had been seen as 'challenging' by the hospital setting which struggled to understand her needs. M needed a quiet space in which she could express herself through art. M's art was described by hospital staff as 'colouring'. During planning with M, one of our staff, who was a skilled artist, took a range of art materials in and worked with M, for short periods only as that is what they would tolerate. It quickly became clear that M needed to be understood as an artist first. We planned with M and advocated for them until they were found their own home. M's mom, who had made a series of complaints over the years to the hospital, got involved in staff selection and training. M has lived successfully in their own home for 3 years now. Their home was designed with M's art in mind as they do this every day. It was also planned so that it was in a location where they could take regular walks and in a quiet location.

## J

J has lived in a hospital setting for most of the last 10 years. When Changing Our Lives first became involved with J they were in long-term segregation and had very little meaningful contact with people other than the hospital team. We began meeting with J over Zoom and then in person, supporting them to think about the future and having a home and life in the community. J gradually moved out of long term segregation and a property was identified for them.

We have:

- Supported J and the staff team to manage their anxiety while they wait for a provider to be identified, for example through designing social stories and regular conversations over Zoom where J looks at photos of their house and the area.
- Made sure that J is involved in the journey towards moving out of hospital in a way that suits them.
- Facilitated regular person centred planning meetings with J, where they talk freely, at their own pace, about their future. J has enjoyed these meetings and their staff have been surprised that they stay for so long.
- Made sure that J is supported to visit their house regularly and begin to get to know the area.
- Built up an album of photos and video messages of J's journey so far that they can take with them and can be used to help their new staff team get to know them.
- We are working with J's parent, the social worker and the hospital advocate to ensure that the right people are employed to support J, and that they receive training that is co-designed with J and their parent.

# Why Are We Stuck in Hospital?

It is over 10 years since Winterbourne View, the abuse scandal that led to the creation of NHS England's Transforming Care programme. This programme aims to improve care and services for people with learning disabilities and autistic people and reduce inappropriate admissions and length of stay for people in Assessment and Treatment Units (ATUs) and secure hospital settings. Despite Transforming Care, numerous reports, reviews, additional funding and some high profile media cases, there remain over 2000 people with learning disabilities and autistic people in long-stay settings.

We are working with The University of Birmingham on a two year National institute for Health Research funded study to explore why people spend so much time in hospital. The aim of the study is to try and understand the issues from the point of view of people themselves, families, hospital staff and commissioners. The team were recently successful in gaining additional funding through a social care extension bid which will mean that we can also seek the views of social workers, advocates and providers on the issue.

One year into the study we have spoken to 25 people with learning disabilities or autistic people in three different long-stay hospitals across the country to try to understand their often lengthy journeys through "the system", what they think would help them move out of hospital quicker and what they want their life to look like in the future. We will revisit people one year after meeting them to see if their lives have changed and if they are any closer to living the life they want.



As part of the study we have recruited and facilitated a reference group of people with learning disabilities, autistic people and family carers. The group includes people who have experience of being in such hospitals themselves. They have helped to shape the approach the researchers have taken when speaking to people, sense-checked early findings and will be involved in helping to plan the training guide for professionals, one of the outputs of the study.

*"This research tackles a topic that is often overlooked. People with learning disabilities and autistic people can be sectioned for long periods of time, often years. This is usually because of unmet need and because of a higher likelihood of mental health difficulties compared to people who are considered neurotypical. Despite an increased awareness of mental health in the media, there is little emphasis on how this translates to people with learning disabilities or autistic people. People like myself who are neurodiverse often have difficulties with communication. If our communication is significantly or consistently misunderstood by those around us we may communicate our frustration through our behaviour, and this can lead to us being labelled as challenging. Eventually this breakdown in communication can lead to some people being sectioned."*

- Zeze, Reference Group Member

There is also an advisory board of professionals from across the sector including policy and practice leads from a wide range of voluntary, statutory, legal and academic bodies bringing a wealth and breadth of experience to support the research team.

The study concludes at the end of 2022 and the report, training guide and film will be launched in the first half of 2023. We have also secured some additional funding to work with the Ikon art gallery in Birmingham to organise and host an exhibition which will try to promote the findings of the study and raise these issues with a public audience.



## The Hospital to Home book series

For people with learning disabilities and autistic people living in hospitals, irrespective of whether these are assessment and treatment units or secure services, the two main issues that typically hit the headlines are either abuse scandals, which happen all too often or the numbers of people still living in these units, which remain inordinately high. When a scandal hits, the occasional MP or minister is outraged and the story remains topical for a while. This media energy soon fades and fizzles out and the people in hospital are forgotten once more.

What we rarely hear is the story of the people themselves and the good practice that exists around the country when clinicians and professionals in hospitals adopt approaches which enable the individual to move into their own homes. As an organisation, we have felt the frustration and, at times, the outrage when we are planning or advocating for an individual who is trapped in the system. However, one way to gain traction in the system is to share people's stories in order to show real examples of what is possible. We are still coming across professionals who just don't believe or can't see how the individual they are working with could live their life in their own home.

With this in mind, we made a decision to launch a book series called 'Hospital to Home' which will record the experiences of both individuals who have left the hospital and are settled in their own home, as well as individuals who are still within hospital settings, but whose transition needs to be slower in order for the eventual move to be sustained.

Each story is told from the individual and/or the family's perspective.

Beth's story was the first in the Hospital to Home book launched on Human Rights day, 10th December 2021. The story has been written by Beth and Beth's dad, Jeremy. Beth is a vibrant young woman who has been failed by the system and has, as a consequence, ended up in 16 different settings in 7 years, many far from home, and spent just under 3 years in locked seclusion, because specialist services could not meet her needs and did not understand how to work with her to get the best out of her. Beth now lives in a new setting, provided by Mersey Care, NHS Foundation Trust, where she is given a great deal of control over her daily life choices and where staff understand Beth's autism and adapt to her, rather than expecting Beth to adapt to them. Although Beth is still on the journey to independence in her own home, her progress in such a short space of time is testament to her own resilience, her father's national campaigning and the work of the staff team around her who take their lead from Beth in their support of her.





## Anti-racism projects

Anti-racism has been a key commitment of the organisation from our early days; our approach embraces both equality and equity.

The Equality and Human Rights Commission describe equality as: "Ensuring that every individual has an equal opportunity to make the most of their lives and talents."

Equity is about giving people what they need in order to make things fairer and plays a key role in achieving equality. This means taking into account systemic inequalities to ensure that everyone has access to the same opportunities and outcomes.

For us, this means targeting our resources to vital areas of work and alongside communities significantly more likely to experience social injustice and health inequalities on multiple levels throughout their lifetime, resulting in poorer outcomes and even premature death.

Pursuing equity in our work is necessary in tackling the personal, interpersonal, institutional and structural discrimination that these communities experience and ensuring that they have the same opportunities to live an ordinary life as the rest of society.

This year, the following project particularly highlighted our anti-racist approach.

## Equal Treatment

In 2022 we are one of 3 organisations delivering an NHSE/NHSi funded project called Equal Treatment. The work is hosted by Learning Disability England who are working in partnership with the Race Equality Foundation. At the core this project is about understanding and tackling racism.

The area of work we are leading on aims to inform and support self-advocacy groups and organisations made up of people with learning disabilities to overcome barriers and taboos in relation to understanding and speaking up about racism. It will strengthen those groups and organisations to move towards anti-racist practice, ensuring representation of people from minority ethnic communities, and challenges to the inequalities faced by people from minority ethnic communities.

In bringing self-advocates together from these organisations, our programme includes a historical perspective, discusses how racism impacts attitudes and behaviour, explores real stories and considers the challenges and solutions. Running parallel to this, will be work with CEOs, Trustees, Directors etc. from across the organisations to look at culture, practice and governance to achieving anti-racist practice. This will include learning from our own experience as an organisation, exploring tools, approaches and attitudes to achieving this.





## 200 Lives

People with learning disabilities are one of the most socially excluded groups in our society, the legacy of historical segregation that denied people their own home, choice and control and a decent income. Having a home of your own and the right support are keys to being part of the community, being accepted as equal citizens and living an ordinary life.

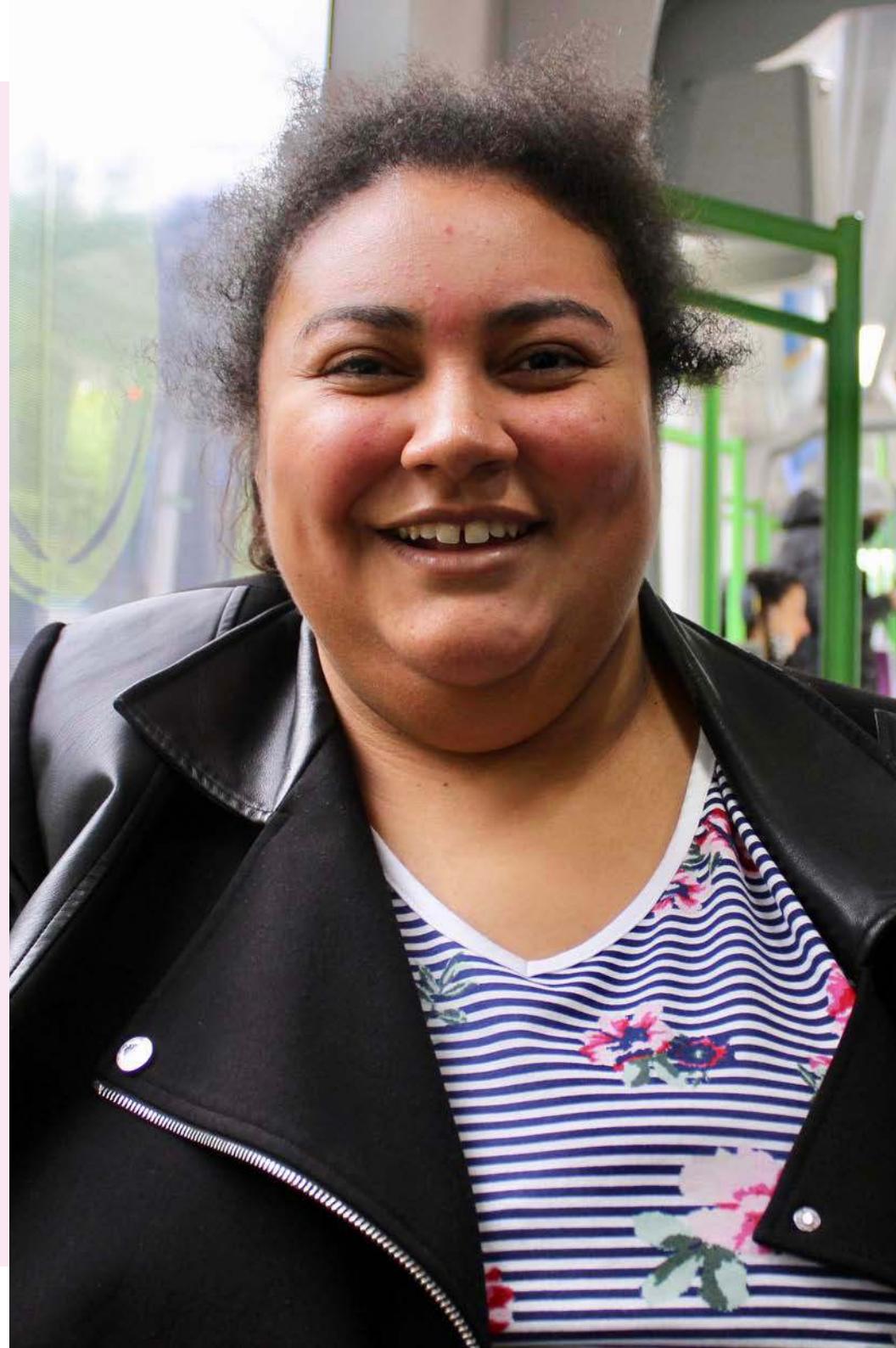
People with learning disabilities who want or need to move out of the family home, are usually offered either residential care or supported living. There are some key differences between the two approaches. In a supported living setting, the person has their own tenancy agreement, they are responsible for their own bills and cost of living, and their support is provided separately to their accommodation. In residential care, the person has a license to occupy a room, their care and accommodation is combined, and bills are covered by the care provider. People in supported living have access to a wider menu of benefits than those in residential care. In theory, supported living should give individuals more rights and control over their lives: where they live, who they live with (if anyone), the support they get, and how they live their lives. As a result, since supported living was first introduced as a concept in the 1990's, there has been a steady shift away from residential care towards supported living.

Councils spend nearly £3 billion a year on supported living and residential care for adults with learning disabilities, but very little is known about how good these two approaches are in reality, and how much they really cost. The National Institute for Health Research funded Manchester Metropolitan University, National Development Team for Inclusion, London School of Economics and Changing Our Lives to examine the quality and costs of supported living and residential care for 200 adults with learning disabilities aged 18-64 years. The research aimed to get good, up-to-date evidence on the quality and costs of supported living and residential care services.

As part of the wider research, Changing Our Lives carried out Quality of Life reviews with 16 people. The reviews aimed to act as an additional layer of inquiry to the data collected by the research team, as well as providing a different perspective on quality from people with lived experience of learning disabilities. A Quality of Life Review report was written for each person as well as a summary report that outlined themes that emerged from the individual reviews.

Each Quality of Life review aimed to measure how each provider enables disabled people to lead an ordinary life. The reviews focussed on the following areas of the Quality of Life Standards: My Home, Being in Control of my Life, Having a Full Life and The Way People Work with Me.

The findings from the Quality of Life Reviews aligned with those of the wider research team. The themes and issues of note from the Quality of Life reviews reflect potential differences across the two models of support and wider attitudes and values around people with learning disabilities which are still too prevalent within services and across society as a whole.





Some of the themes and issues of note were that people in supported living seem to have more control over their daily lives and are more involved in running their lives than people in residential care, and people with higher levels of staff support who live in supported living seem to have more spontaneous, personalised and varied lives. The review team found very few examples of people having non disabled friends, being in paid work, having roles that contribute to their community and having ambitions and goals beyond their leisure interests across both models of support.

The findings from the Quality of Life Reviews have been incorporated into the wider findings of the research and a report has been written which will be published in spring 2022.

# Got My Back Learning Event and Twitter Chat

For several years, Changing Our Lives has worked with national partners to raise awareness and challenge inequalities surrounding postural care for people with reduced mobility. A healthy posture is important for us all. Most of us are born with a symmetrical body shape, but for people with reduced mobility it is more difficult to maintain a healthy posture throughout life. This means that over time, some people with reduced mobility develop body shape distortions. Postural care is any intervention which protects a person's body shape and reduces their risk of health complications associated with distortion. For some people with learning disabilities, in particular those with the label of profound and multiple learning disabilities (PMLD) poor posture has been linked to poorer quality of life and an increased risk of premature death (Heslop et al, 2020).

Through our work with disabled people we have heard that best practice in postural care is not common knowledge among the families of people with the label of PMLD, and in some areas of the UK, it is not even common knowledge among the health professionals who work with them. At Changing Our Lives, much of our wider health inequalities work over the last few years has happened alongside learning disability nurses (Changing Our Lives, 2021). We see learning disability nurses as uniquely placed to be able to spot poor posture and draw together families and professionals to make positive changes to a person's postural care.



In 2021, we held an online postural care learning event aimed at learning disability nurses. The event was attended by 120 professionals and students and the catch-up recording was watched over 200 times. With guest speakers Rachel Wright (Born at the Right Time), Leanne Briggs (Teesside University) and Alistair Beverley (The LD Physio) the learning event brought together family perspectives, practical tips and evidence-based information. Knowing that postural care is fundamental to tackling health inequalities for people with learning disabilities, the event was targeted particularly to learning disability nursing students, and many students and lecturers took up the offer from Andrea Page at Birmingham City University to learn more about the unique way that they embed postural care knowledge into the student nursing syllabus.

Following on from the success of the online event, Changing Our Lives hosted a live Twitter Chat with Rachel Wright and Sarah Clayton (Simple Stuff Works) to bring together people, families and professionals from a range of backgrounds to discuss the barriers and solutions to getting good postural care for all. This Twitter chat was well attended and as a result, Kingston University held a postural care skills session for their learning disability nursing students. Postural care remains a key priority for Changing Our Lives in our broader health inequalities work, and next we hope to share awareness and practical skills with social care professionals such as social workers and supported living providers.

You can watch the recording of the learning session here: <https://www.youtube.com/watch?v=ATbxSfa8roU>

#### References:

Changing Our Lives (2021), Best practice in learning disability nursing [<https://www.changingourlives.org/blog/best-practice-in-learning-disability-nursing>]

Heslop, P. et al (2020), University of Bristol LeDeR annual report [<https://www.england.nhs.uk/wp-content/uploads/2021/06/LeDeR-bristol-annual-report-2020.pdf>]



## Ordinary Life Stories

In Changing Our Lives, 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. An ordinary life, first coined by the King's Fund in their seminal report *An Ordinary Life* (Kings Fund 1980), promoted the concept that people with learning disabilities should live in ordinary houses, in ordinary streets and be part of ordinary communities.

Disabled people and people with lived experience of mental health difficulties are often faced with barriers which make everyday, ordinary things like living in their own home, having a good job or having a partner difficult to achieve. Some of these barriers may be internal, but more often than not society places barriers in the way of individuals. These barriers can be other people's attitudes, a lack of creative thinking or physical barriers.

We know that an ordinary life is achievable for everyone, so our series of Ordinary Life Stories have for many years highlighted the lives of disabled people. Although these lives are ordinary, the stories often focus on the creativity, dedication and passion that a person and those around them have applied to get them where they are today.

In November 2021, Changing Our Lives celebrated the lives of 3 Sandwell residents with learning disabilities by releasing their Ordinary Life Stories books both online and at an in-person launch in the historic surroundings of Central Library, West Bromwich.

In her story, Working 9 to 5, Sonja reflects on how important employment is in her life, and the long road she has taken to find the support and adaptations that make her career a success. Stephen's story, Seize the Day charts the changes that have happened throughout his life that have led to him being an independent man in his 50s living in his own home. Mandy is an accomplished athlete nationally with the Special Olympics, and her story offers readers a flavour of her personality as A Force of Nature, who has made the move from inpatient hospitals to being in her own home.

The launch was opened by Cllr Bob Piper and attended by Cllr Kerrie Carmichael along with friends and families of Stephen, Sonja and Mandy. After arriving in style in a limousine, all 3 took questions about their book, followed by a book signing. Taking place in the heart of the community in West Bromwich at the end of a long year of COVID-19 restrictions, the event was a much-needed chance for people to get together and celebrate, and for the 3 people whose stories were shared, it was a chance to be recognised for their unique personalities, passions and achievements. As Mandy said "The book launch was lovely. My book is really powerful. Thank you for helping me with my book. When you read it, it's me to a tee!"

You can read all of our Ordinary Life Stories on our website: <https://www.changingourlives.org/Blogs/ordinarylifestories>

#### References

Kings Fund. (1980). *An Ordinary Life: Comprehensive locally based residential services for mentally handicapped people*, London: Kings Fund.





## Digital Lifelines

Even before the COVID-19 pandemic, people with learning disabilities in the UK were experiencing digital exclusion. Digital exclusion refers to the barriers such as lack of internet access, lack of technology or lack of skills and confidence that prevent some people navigating the digital world (Good Things Foundation, 2021). In today's increasingly online society, digital exclusion impacts on people's health outcomes both directly, in accessing health services (Healthwatch, 2021) and indirectly, as digital access impacts on employment and social participation (NHS Digital, 2021). As the national COVID-19 restrictions kept people at home, Changing Our Lives continued to work with people with learning disabilities, and found that many were being left behind by the surge in socialising, shopping and working online, due in large part to a lack of access to suitable technology or support to get to grips with it.

Changing Our Lives began proactively seeking grants to ensure that digital technology is part of the lives of people we work with and in April we were selected to be a community partner for the Digital Lifeline programme, coordinated by the Good Things Foundation and funded by the Department of Digital, Culture, Media and Sport. We distributed 36 tablets to people with learning disabilities across England and offered them internet data and support with getting online. We supported people to develop their digital skills and to use their tablets to connect with friends and family, including some who hadn't seen loved ones since before the pandemic started. We used people's new devices and their emerging skills to link them in with other projects, such as our virtual Speakeasy nights which brought professional performers into the homes of people with learning disabilities in Sandwell.

People who received a tablet through Digital Lifelines used their new tablets to catch up with friends, work on fitness goals, contribute to research over Zoom with Changing Our Lives, get back into working from home, take part in hobbies they had been missing from before lockdown and learn new skills.

One person, who had never had a tablet before, and didn't already have Wi-Fi at home, received a tablet through Digital Lifelines. After getting the hang of listening to his favourite music online and getting back in touch with friends, him and his mom decided to get Wi-Fi installed at home and even bought a smart TV. He was using his tablet to get back into his DJ-ing, which he hadn't done since before lockdown.

Another person was nervous about receiving her tablet as neither her nor her parents had ever used one before. With support from Changing Our Lives, she was soon up and running and now enjoys using her tablet to watch films, chat to friends over Facebook messenger and get involved in events with Changing Our Lives Zoom events. Her mom commented, "The tablet has been a godsend to us during the pandemic."

Following the success of the Digital Lifelines project, Changing Our Lives made a commitment in our strategic planning to continue our digital inclusion work for the next 2 years. We have built on the skills and confidence people gained to set up other projects such as our FitBit work and have started to share our outcomes strategically with local partners in Sandwell to call for digital inclusion to be embedded in local plans for people with learning disabilities.

#### References:

Good Things Foundation (2021), Digital exclusion & health inequalities [https://www.goodthingsfoundation.org/wp-content/uploads/2021/08/Good-Things-Foundation-2021---Digital-Exclusion-and-Health-Inequalities-Briefing-Paper.pdf]

Healthwatch (2021), Locked Out: Digitally excluded people's experiences of remote GP appointments [https://www.healthwatch.co.uk/report/2021-06-16/locked-out-digitally-excluded-peoples-experiences-remote-gp-appointments]

NHS Digital (2021), Why digital inclusion matters to health and social care [https://digital.nhs.uk/about-nhs-digital/our-work/digital-inclusion/digital-inclusion-in-health-and-social-care]

# Fitbit project

37.5% of people with a learning disability were classified as obese, this was also greater than those without a learning disability (29.9%).

- NHS Digital, 2019

Based on our work with people, we know that people with learning disabilities living in the Black Country, like the rest of England, experience significant health inequalities and sometimes are not given opportunities or access to healthy life styles. The pandemic has only exacerbated this situation as people with learning disabilities have been isolating, many not leaving their home for over 14 months and not accessing any form of physical exercise.

Through funding from Active Black Country, we have distributed 30 Fitbits to people with learning disabilities throughout the Black Country in order to motivate individuals to get active and connect with their peers or the wider community. Not only are the Fitbits encouraging people to move more, they are also allowing individuals the option to monitor their overall health and wellbeing through tracking their sleep, menstrual health and mood. Those who use Facebook, have been posting their progress with their Fitbits on our community Facebook page. In sharing their progress and Fitbit app statistics with others, people continue to motivate each other to increase their daily steps and exercise. This work has given us the opportunity to explore how this technology can impact on both the overall quality of life of people and has resulted in improved health outcomes.





*"They were enthusiastic and interested to know how many steps they'd done, which encourages them to progress in their abilities to take that one extra mile every time they were being active. This has improved their mental wellbeing and stamina in general."*

*"I've started to feel much fitter in myself. I feel energy from exercising more. It keeps me going."*

References:

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/health-inequalities>

# Common Ground

The proportion of disabled people (13.3%) who report feeling lonely "often or always" is almost four times that of non-disabled people (3.4%), with the greatest disparity for young adults, aged 16 to 24 years old.  
(ONS, 2019)

With Headstart funding, throughout 2021 and 2022, we have been working on our Common Ground project in Wolverhampton. Common Ground uses 'Community Connecting' as an approach to tackle youth loneliness, through building 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. Therefore, we don't connect young disabled people into segregated services, instead we have built relationships that are grounded in shared interests within communities. By establishing real relationships with real people, the success of these connections will stand the test of time and make a real difference to people's lives. It is through using this approach that young people have found solutions to overcoming loneliness by developing their skills and improving their mental and general wellbeing. Community connecting allows us to build on the strengths of young people, while strengthening their voice to make the change they need in their lives.





### Individual connecting work

The pandemic has had damning effects on the mental health of many of the young people we work with. Each young person's situation is unique and for some, the negative implications of isolating and shielding have impacted upon their confidence. We have worked on a 1:1 basis with 9 young disabled people, including young autistic people and young people with learning and physical disabilities, getting to know them over time by building trusted relationships. By establishing connections in the local area, we have facilitated individual connections for these young people, some within mainstream opportunities and some with individuals in the community who share a common interest. Through individual connecting work, a range of outcomes were achieved for young people. For one young man, our involvement triggered thoughts about doing things as a young man independently, both in himself and his family.

*"You've got me thinking that [my son] doesn't do anything outside of school and services. I want to prepare him for the real world."*

#### An example of individual connecting work:

After getting involved in arts opportunities as part of Common Ground, through 1:1 support from Changing Our Lives, one young person was successful in applying for a volunteering role at Wolverhampton Art Gallery and is now taking steps towards a career in the arts. This experience has enabled them to build their self-esteem and focus on their future.

*"I'm just so grateful to have made such great connections through Changing Our Lives. Being involved in something that brings me joy and actually changes the way I feel and what I feel has been a great experience. This project will have lasting effects on me and I often reflect on what I have done and have been able to achieve."*

### **Group work with a local school and college**

Throughout the course of the project we developed close relationships with a special school and college to deliver bespoke programmes of work to 18 young people. The young people in these classes are approaching transition from school to college or from college to work, which can be a daunting and unfamiliar time, as young people prepare to leave a familiar environment for pastures new. Through facilitating a series of custom workshops that focussed on their goals and aspirations, young people learnt how building connections in the community can increase confidence and resilience and contribute to their goals for the future.

This work has prompted conversations within the special school about the importance of friendships and connections for these young people and staff are exploring how this practice can be embedded to benefit future generations of pupils.

*"It's been a real learning curve for us on how to give the kids a voice and talk about their goals for the future [and] exploring how isolated [they] are outside of school."*

*"To make these connections happen for young people, we pledge to be resilient and adaptable to change and to grab opportunities for further community mapping in both hands and to open the world up to our young people."*

### References:

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabilitywellbeingandlonelinessuk/2019>

# Beyond the Stigma

Having good mental health is central to our wellbeing and building strong and resilient communities plays a vital role in this. Beyond the Stigma brought together South Asian women from across Sandwell to share their stories in order to challenge the stigma that surrounds mental health within their communities and encourage others to engage in the conversation through a social media campaign and digital book.

The project took place during the height of the coronavirus pandemic, a time in which mental health became a hot topic of conversation. Though conversations about mental health are more commonplace in the UK today, we know through our work, there is still widespread stigma within South Asian communities. The way these women have experienced mental health difficulties is no different to the rest of society, however, their encounter is often set against a background of cultural expectations which include pressures from family relating to gender biased customs.

As part of the project Changing Our Lives facilitated virtual creative workshops with award winning poet and spoken word artist, Shareefa Energy (<https://www.shareefaelogy.com>), and explored how the arts are a powerful way to share experiences and challenge myths. The workshops supported self-expression and celebrated identity and value, giving women the opportunity to explore ideas and develop their own writing and creative work.





A collection of personal stories and creative writing was then developed by the women, resulting in the publication of a digital book, Beyond the Stigma: "Lok Ki Kehnge?" Their work was shared throughout the course of the social media campaign in a variety of mediums, including video interviews, and encouraged the others to join the conversation.

*"Intergenerational trauma - search it, read about it, become aware of it. It doesn't just exist in our communities but it prospers in our communities, because those norms and values that are passed down to us, seemingly to keep our culture and traditions alive, have taught us to suffer in silence."*



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