

A man with a short buzz cut, smiling, wearing a blue t-shirt and a dark green jacket. He is standing in front of a building under construction, which is covered in blue scaffolding. The background shows other buildings and a cloudy sky.

Annual Report 2022-2023

Annual Report

2022-2023

Foreword

2022 was Changing Our Lives' 20th anniversary year.

In April 2002, I worked alongside people with learning disabilities to form the charity. Looking back, we were working in an environment in which most people with learning disabilities lived in residential settings, with people they did not choose to live with and often did not get along with. Everyday choices were more often than not denied to people; they did not have the opportunity to choose what to wear, what to eat, when to get up in the morning or go to bed at night, occasionally you would come across 2 people sharing a bedroom with a curtain dividing the beds, and sex was obviously off the table!

Fast forward 20 years to 2022 and, although people are still having to fight for many basic choices and rights, things have improved. People now live in their own homes with support, some people, although not enough by far, have paid employment and people have relationships, with a few getting married.



Although things have improved, there is still as much to change today as in 2002 in many ways. On average 2000 people with learning disabilities and autistic people are still trapped in locked hospitals each year - so you could argue the old long-stay hospitals never really closed. This therefore remains a priority for us and in 2022-2023 we worked both on an individual level enabling people to move out into their own homes and on a strategic level, alongside the University of Birmingham on the *Why Are We Stuck in Hospital* research project.

People with learning disabilities are still dying prematurely as on average men with learning disabilities die 22 years younger than men in the general population and women with learning disabilities die 26 years younger than women in the general population. These premature deaths are avoidable deaths. In 2022-2023 health inequalities therefore remained a priority, with us focusing on the postural care checklist for learning disability nurses and a project called Opening Doors which explored the role of the learning disability nurse in locked in-patient hospitals.

We also continued our anti-racist work, prioritising three projects. The Common Ground project produced a book and portrait exhibition of the lives of seven disabled community leaders, the Equal Treatment anti-racist training programme was delivered to people with learning disabilities across England and the Barbershop Stories project facilitated conversations around mental health and identity in the Black male community in Sandwell.

We are immensely proud that this work is coproduced with disabled people and that disabled people are paid for their work with us, as they have been for the past 20 years.

Jayne Leeson MBE
Changing Our Lives CEO

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

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Who we are

Changing Our Lives works with people with learning disabilities and autistic people, as well as people with lived experience of mental health difficulties of all ages on a range of projects that seek to combat social injustice and health inequalities and to develop long-lasting solutions. However, in many areas of our work we choose 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

Since we were established in 2002, we have used a coproduced approach, working in partnership with disabled people and people with lived experience of mental health difficulties to shape and deliver projects. In 2022-2023 we continue to be committed to this approach.

From day one, Changing Our Lives has been committed to paying disabled people for work with the organisation. However, although we are fiercely committed to paying people, having relevant lived experience is not enough. We head hunt people based their skills and knowledge in a variety of different fields, and most importantly because they have a shared vision of human rights and an ordinary life with us.





In 2022-2023 we paid 20 disabled people across a range of projects.

50% of these people had a learning disability

35% of these people had a physical disability

50% of these people were autistic

45% of these people were from minority ethnic communities

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.





Our values

The following values guide all of us at Changing Our Lives, as they shape the culture of the organisation, the way we behave and the way we work to challenge social injustice and develop solutions based on equality and an improved quality of life.

Equal Rights

All people are citizens in their own right and have the same human, legal and civil rights as each other.

People First

All people should be seen as people first. We should not be seen simply in relation to impairment or a mental health difficulty. These labels should not be used to define us as a person, segregate us, remove us from society, or limit us in any way.

Independence

We are all inter-dependent; we all need to connect with others in our lives. No one is too disabled or too affected by mental health difficulties to lead an independent life. Being independent means having choice and control over your own life with as much or as little support as you need. It does not mean being on your own and doing everything for yourself.

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* (King's 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 and non-pathologising perspectives. Just as we all have physical health, so we have mental health.

The recovery 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

Non-pathologising perspectives of emotional distress acknowledge the causal role of social and relational conflicts, abuses, difficult life experiences and adversities, social inequalities, oppression and injustices. Consequently, individual solutions are not enough. Wide ranging and sustainable improvements in mental health will only come from social change that strives for equity, social justice and a fairer society.



Our Work

2022-2023

A photograph of a hospital corridor. The walls are a light blue-grey color. On the left, there are two closed doors with small windows. A framed picture hangs on the wall between them. At the end of the corridor, there is a window with yellow vertical blinds, through which some greenery is visible. Below the window is a white radiator. To the right of the window, a dark door is slightly ajar, revealing a small square window in its upper part. The floor is dark and reflective. The overall lighting is dim, with the primary light source being the window.

**Working with people
trapped in locked hospitals**

A key area of our work and our passion as a team is the plight of people with learning disabilities and autistic people living trapped in long-stay hospitals across the country. It is 12 years since Winterbourne View, the abuse scandal that led to the creation of the government's Transforming Care programme. The 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. The average length of stay is 5 years, however many of the individuals we work with have been in hospital 15, 20 and in some cases 40+ years.

We aim to work at both a strategic and individual level to challenge these injustices. Our *Why Are We Stuck in Hospital?* research project tackles the issues on a strategic level, whereas our Future Planning work champions the rights of individuals to leave hospital and lead ordinary lives, in ordinary homes, in ordinary streets.



2000 PEOPLE ARE LOCKED UP

350 HAVE BEEN DETAINED FOR OVER A DECADE

26,000 REPORTED USES OF RESTRICTIVE
PRACTICES OVER ONE YEAR

ALL HAVE LEARNING DISABILITIES
AND/OR AUTISM

WHY ARE THEY STUCK IN HOSPITAL?

i'm SO far
away from
my mum



Why Are We Stuck in Hospital?

Over the last two years we have worked alongside the University of Birmingham on a two-year National Institute for Health and Care Research funded study to explore why people spend so much time in hospital. The aim of the study was to try and understand the issues from the point of view of people themselves, families, hospital staff, commissioners, social workers, advocates and social care providers who support people when they leave hospital. We spoke to 27 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 thought would help them move out of hospital quicker and what they wanted their life to look like in the future. We went back to see people one year after first meeting them to see if their lives had changed and if they were any closer to living the life they want.

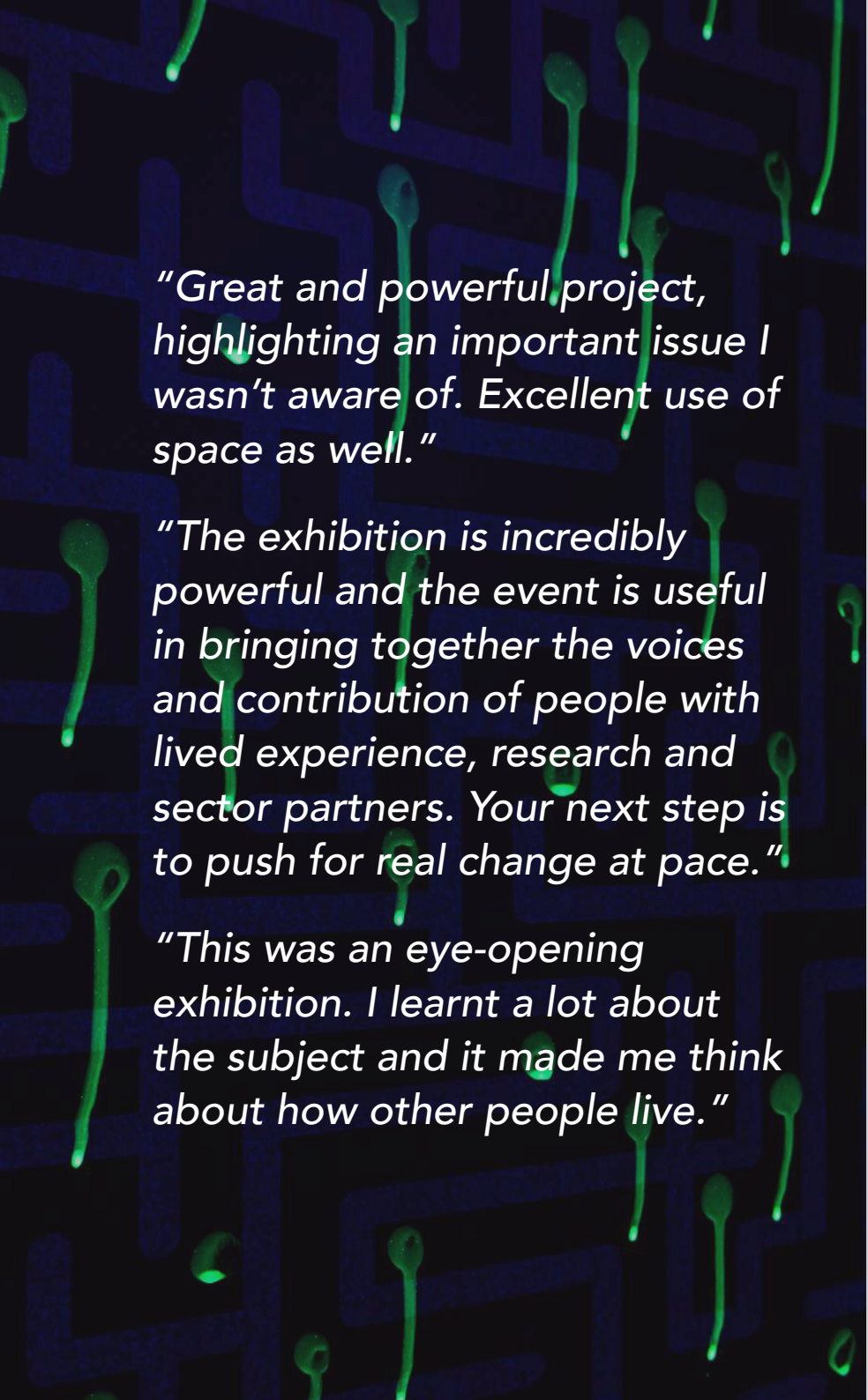
We used what people told us to create a guide that has been sent out to all heads of adult social care and health trusts in the country. We produced an accessible film version of the guide as well as an easy read version for people and families. We also produced a training film for social care professionals. All of these resources are hosted on the Social Care Institute for Excellence website as well on those of Changing Our Lives and The University of Birmingham.



In order to maximise the impact of the work and to ensure that conversations around the scandal of people being stuck in hospital took place outside of the world of health and social care we worked with Ikon, Birmingham's contemporary art gallery. They commissioned local artist Foka Wolf to create a gallery installation, highlighting the issue, that coincided with the launch of the guide as well as promoting the research and exhibition on billboards across Birmingham with the help of creative advertising specialists Jack Arts. Jack Arts estimate that footfall across the billboard sites over the two weeks was in excess of 350,000.

Two launch events were held, one to launch the policy and practice guide to an audience of health and social care professionals and one to launch the exhibition to the public, to discuss issues from the research and the collaboration between the research and the Ikon. The exhibition ran for ten days attracting 3397 visitors. We created an accessible guide to the installation as well as a display based on Matthew's story hosted by the Ikon in their resource room. We created this display using photographs and text from Matthew's story to further educate the gallery audience on the issue.





"Great and powerful project, highlighting an important issue I wasn't aware of. Excellent use of space as well."

"The exhibition is incredibly powerful and the event is useful in bringing together the voices and contribution of people with lived experience, research and sector partners. Your next step is to push for real change at pace."

"This was an eye-opening exhibition. I learnt a lot about the subject and it made me think about how other people live."

Both the research and the exhibition attracted a lot of publicity with pieces appearing on the BBC News website and in The Guardian online as well as many articles in local media publications.

To date the research team have presented the work to multiple audiences including:

- Royal College of Psychiatrists network meetings
- British Association of Social Workers' 'Homes not Hospital' campaign
- British Association of Social Workers Black Country branch
- Skills for Care (exploring commissioning competencies on behalf of a Ministerial Working Group)
- National Commissioning Conference

They are also due to present at a number of national and international conferences:

- British Association of Social Workers national conference
- Health Services Research UK conference
- International Conference on Integrated Care (ICIC23), Antwerp
- Building the Right Support Community of Practice (via Local Government Association)
- Mental Diversity Law Network: 'Why haven't we Transformed Care yet?'
- Making Research Count, King's College London
- Asia Pacific Conference on Integrated Care, Australia
- National Advocacy Conference



Future Planning

Over the last year, Changing Our Lives has worked with nine people who are or have been trapped in hospital settings around the UK. Typically, when people are trapped in in-patient units, there are multiple professionals involved in their lives. On paper, they all have the same goal of moving the person out of hospital, but despite this, the average length of hospital stay is around five years with some having been in hospital for over forty years.

Our approach, firmly rooted in the social model of disability and the principles of coproduction rather than the restrictive requirements of professional roles, is unique. When we work with individuals the questions we ask are: what do I need to do to move the person closer to living in their own home and what do I need to do to make a difference to the person's life now? Through a combination of Person Centred Planning, rights based advocacy, facilitation and problem solving we work flexibly to do just that. For one person, this might involve creating a person centred plan and ensuring they have a committed team around them working towards shared outcomes. For someone else, we may be involved for several years, with various changes and transitions en route.

Improving quality of life in hospital

Although our sights are always set on the ultimate aim of the person moving into a home of their own in the community, we also look to immediate and short term improvements that make a difference to the person in their current environment. Some of the outcomes achieved over the past year include: ensuring one person had reasonable access to community leave, supporting one person to expedite their dental appointment on the basis of the negative impact on their dysphagia and wellbeing, challenging the rationale behind delaying home visits for one person, linking one person to an opportunity in the community after twenty years in hospital and securing expertise from an outside organisation for another person in hospital that will ensure appropriate positive behavioural support throughout their transition into the community. For one person, there was a significant shift in the attitude of the wider multi-disciplinary team from seeing discharge as highly unlikely for the person to recognising that this was a real possibility with the right support. This had a positive impact on the person and their own sense of hope and optimism for the future.

Moving out of hospital

Our work with individuals is exemplified by B, who moved out of hospital into their own home a few months ago after being in and out of hospitals for over twenty years. B was in long term segregation when Changing Our Lives got involved.

Our first priority was relationship building. In practice, this meant spending time with B getting to know them as a person, rather than purely as a list of labels, diagnoses and problem behaviours. Getting out of in-patient units is rarely quick or straightforward so an important part of the relationship was to be someone who consistently reflected the belief that they could and would move out of hospital.

We also spent time talking to the people in B's life, forging alliances with key players and those with influence and power to make change happen. Further down the line, we worked closely with the identified provider, ensuring that B's transition into their own home was planned with their needs at the centre. A key part of this was facilitating a training day for the new staff team with B's social worker, previous hospital advocate and B's mum.



Part and parcel of working in coproduction is being ready to be flexible, creative and responsive to what is in front of you. Working with B often meant picking up a range of tasks to make sure that they moved closer to, and eventually out of hospital. That could mean anything from coordinating visits for B to see their new home and the local area to creating social stories to support B to understand the journey out of hospital.

Having acquired the 'complex' label, B was someone who generated a lot of meetings, none of which they were part of in any way. In contrast, we used a bespoke approach to person centred planning. For B, this meant facilitating small informal workshops, where B was in control: deciding who to invite, what to talk about and setting the pace of the conversations that happened. In practice, this often meant flitting between talking about B's life and future to watching snippets of favourite police dramas or song. This worked for B, who chose to stay for 2 - 3 hours each time, unheard of at any other meeting. A wealth of information was generated which was used to develop a person centred plan in written and film format.

After many twists and turns and half a lifetime spent in institutions, B has now moved in to their own home with their own staff team and is beginning to live the ordinary life we are all entitled to.



Anti-racism projects



Colour Between the Lines

Drawing on oral history approaches and funded by the Heritage Lottery, *Colour Between the Lines* charts the individual development and successes of 7 disabled individuals from minority ethnic communities who, in spite of societal prejudices and discrimination towards race and disability, have established successful and thriving lives.

The project emerged from an awareness of the relative invisibility of disabled people from minority ethnic communities in society and in oral histories, and the need to challenge these gaps in the narrative.

As the individuals involved with this project sit at the intersection between disability discrimination and racism, they were able to provide a unique vantage point on the role ethnicity plays in disability and self-advocacy movements.

Working alongside these 7 individuals, we produced a written publication, a short film and a series of portraits, which were launched in July 2022 at the Black Cultural Archives in Brixton as one of a series of events marking the 20 year anniversary of Changing Our Lives.



Colour Between the Lines (2022)

Read the full publication [here](#)





Equal Treatment

This NHS England and NHS Improvement funded project was hosted by Learning Disability England in partnership with the Race Equality Foundation. It sits within a wider programme of work that Race Equality Foundation is leading on, finding evidence and examples of what will help stop racism or unequal treatment.

The Changing Our Lives strand of Equal Treatment focused on enabling the self-advocacy movement, which is led by people with learning disabilities speaking out for the rights of their peers, to be more aware of racism and how to proactively tackle it.

Changing Our Lives' philosophy is underpinned by a commitment to anti-racist practice, so this opportunity very much appealed to our core values and approach. Tackling racism head on, we needed to take into account the systematic and structural factors that perpetuate inequalities and we challenged these as part of this programme.

Before starting the work, we expected the sessions to prompt people within self-advocacy organisations to begin thinking about racism in a critical way. However, we found that most people had never been exposed to conversations around racism and this was a starting point for those conversations.

"Thank you for these sessions. If there is any take away for you I hope it is that what you have delivered has been exactly the catalyst we needed."

The training programme was aimed at not only self-advocates with learning disabilities but also management structures within their organisations. It included a historical perspective, discussed how racism impacts attitudes and behaviour, explored real stories and considered the challenges and solutions. A core element was the recognition that people need to be seen and understood as a whole – not simply as a disabled person, but a person whose ethnicity and experience of race will inevitably shape their life experiences.





Feedback from self-advocates, support staff and management following the workshops indicated that not only did they feel they had a better understanding of racism and anti-racism, but they felt more confident in speaking up about and challenging racism. There was increased motivation and determination to engage individually and as part of their organisation in anti-racist actions.

The project resulted in the coproduction of a whole range of resources being made available on our website to the wider public. They include films on racism and anti-racism, a series of mobile phone diaries, 'keys to anti-racism' postcards and easy read documents on reporting racism and being an ally. They can be accessed via the following links:

- ['What is racism?' film](#)
- ['What is anti-racism?' film](#)
- ['Mobile phone diaries' exercise](#)
- ['Keys to anti-racism' postcards](#)
- ['What is an ally?' Easy Read document](#)
- ['Reporting racism' document](#)
- ['Recommended Reading List' document](#)
- [Small Margins Easy Read report](#)

Short Black n Sides

Short Black n Sides is a stream of our work that encompasses a growing range of community based projects that focus on the mental health of men from Black communities.

A positive sense of identity is fundamental to good mental health. Social identification influences how we see ourselves and how we interact with others. If we have a positive view of our identity we are more likely to relate well to others and feel positive emotions about ourselves.

Within the Short Black n Sides work stream, we developed Barbershop Stories, which is a series of seven video diaries where Black men reflect on identity, racism, inequality, career and what can be about positive change. These videos are a window into the lives of Black men striving to make their mark in the world. They tell the stories of how these men see themselves, how they have experienced and navigated different paths, and the impact that society's age old narratives about Black men have imposed on them.

Alongside the series of conversations, the men took part in accompanying work with local youth groups using play and further conversations as a means to role model. They used the basis of their own conversations to further explore young people's thoughts and experiences around identity, mental health, racism and the aspirations they have for themselves.



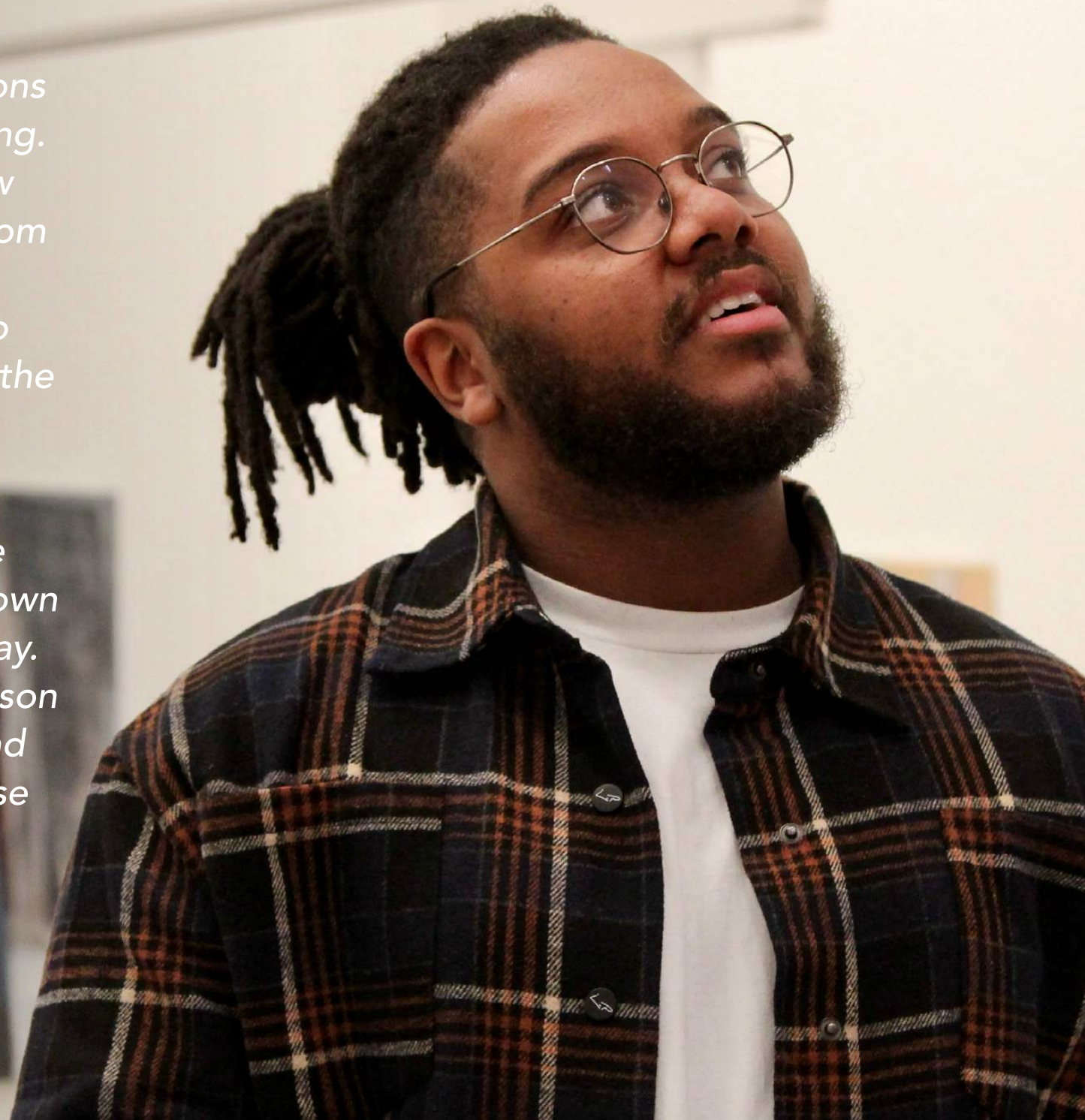


"I've found the conversations therapeutic. What I've taken from them is at times we may feel things we go through are exclusive to us as an individual, but surprisingly many have experienced the same, sometimes worse."

This brings a level of reassurance that you are not alone and it's ok to display a certain level of vulnerability and still be masculine."

"I have found the conversations truly inspirational and up-lifting. From a personal point of view the connection I've gained from everyone within the project has pushed me to do more to provide positive solutions to the issues we face as minoritised communities."

"It was a privilege to see the maturity and intelligence shown by the young men I met today. As a parent of a 14 year old son this gives me so much joy and hope for the future with these young men surely breaking barriers we never got to."





The publication of the 200 Lives report

Between 2020 and 2022 Changing Our Lives worked with Manchester Metropolitan University, the National Development Team for Inclusion and London School of Economics to examine the quality and costs of supported living and residential care for 107 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. Our role in the research was both as partners in the design of the whole project and as reviewers of people's lives using our Quality of Life Review approach. The [full report](#) for this work was published in spring of 2023.



Some of the key findings from the research were that:

- Both supported living and residential care can support people with a wide range of needs. Sometimes residential care was more restrictive, whereas on average, people in supported living had significantly more housing rights such as having their own front door key. However, only a quarter of participants in supported living had all of the housing rights they were entitled to, according to the Real Tenancy Test.
- When accommodation costs are included, residential care is more expensive than supported living.
- Who people live with is more important to them than the building. For lots of people, the company of their housemates and staff was one of their favourite things about where they lived.
- What people want from a house might change throughout their life, as their goals and dreams change. However, most people only move if there is a problem with their current home.
- People found it important to feel part of the local neighbourhood and said that knowing people in the local community helped them to feel safe. Supported living households were more a part of their local community.
- Many people did not have a job, or only worked a few hours. Issues with their benefits could stop people from getting a paid job. Some people in residential care were paid for their work in vouchers.
- People's social networks (the amount of friends and people they know) were quite small in supported living and residential care.

Much of what was found in the research echoes what we have seen in Quality of Life Reviews over the years. We have seen that supported living can give people more choice and control than residential care when done well, but this does not always happen. Further to this, we often see that even where people have 'nice' lives whether in residential or supported living, they are rarely living what could be termed an ordinary life.

The 200 Lives research team has produced a series of messages for commissioners, service providers, housing providers, regulators and policy-makers to consider, which aim to drive improvements in the way services are delivered and people are supported so that their right to an ordinary life is finally realised. The 200 Lives report and other related resources can be accessed via the following [link](#).





Postural care checklist for learning disability nurses

For several years the Learning Disabilities Mortality Review (LeDeR) has emphasised the importance of good postural care in reducing the risk of premature death for all people with learning disabilities, but particularly for those with limited mobility. Changing Our Lives know from working alongside countless people with the label of profound and multiple learning disabilities and their families that good postural care alleviates discomfort, opens up communication and positively impacts on quality of life. Building on the success of our previous postural care work, Changing Our Lives are currently developing a postural care checklist tool for use by learning disability nurses.

Learning disability nurses across clinical and community settings are often at the heart of a person's care. The best learning disability nurses that we have worked alongside are fearless advocates for a person's rights, liaising between people, families and other health and care professionals to improve a person's health and life chances. For this reason, Changing Our Lives believe that learning disability nurses have a valuable role to play in ensuring a person's postural care needs are woven into all areas of their lives.



Building on our work in previous years, which aimed to increase understanding of postural care in learning disability nurses, Changing Our Lives have been working with Simple Stuff Works and Piers Baker, a physiotherapist at Leonard Cheshire to develop a postural care checklist tool for learning disability nurses. Based on the Mansfield Checklist, an accredited tool for identifying postural care needs, and on a document written by Piers for his own work with disabled adults, our postural care checklist will enable learning disability nurses to quickly identify when a person requires input around their postural care, and who is the best professional in their local network to signpost to. It also allows learning disability nurses to review changes over time and has a strong focus on what is important to the person to enable them to lead an ordinary life. A focus group of learning disability nurses have had input into the tool and will be consulted on the final draft before it is launched nationally to learning disability nurses at a webinar.

Opening Doors: Learning disability nursing in forensic hospitals

By definition, the work of forensic nurses in secure settings takes place behind closed doors. Most people, including health and social care professionals in other parts of the system, often know very little about the role of the nurse in these closed settings. When it is highlighted, it is very often in a negative context, linked to a scandal and adverse media reporting. Whilst it is right that poor practice is exposed and condemned, it is also important that good practice is celebrated as it would be in any other setting.

Opening Doors aims to do just that, shining a light on the practice of learning disability nurses working in secure settings. To do this, Changing Our Lives spent time in four different secure hospitals around the country, meeting primarily with nurses, but also with families and patients. During these conversations, nurses discussed how they saw their role, highlighted the challenges they face when trying to implement the improvement standards in secure care and shared examples of practice that had led to real outcomes for the people they support.





Our report, due to be published in 2023, centres around 5 stories of people with learning disabilities, their families and the learning disability nurses who have been instrumental to unlocking an ordinary life in environments that are far from ordinary. These stories are varied in their focus, but all reflect the key qualities that we identified through this work, which would make an effective, compassionate and ambitious learning disability nurse in any team, but which are crucial within the forensic setting.

As a rights based organisation that works alongside autistic individuals and individuals with learning disabilities, often for years at a time, to painstakingly extract them from inpatient settings where their humanity has been eroded, we are well aware that the system which keeps them there is broken. However, we hope that by showing what is possible when good nurses do their job well - using not just the knowledge and skills they have acquired through their training but through their own personal values and attributes - we can contribute in a positive way to the conversation, and showcase the art of the possible.

Environmental Impact Statement 2022-2023



Changing Our Lives is committed to minimising the impact of our activities on the environment. Where appropriate we minimise travel, for example by organising travel so trips are geographically planned. However face to face work is vitally important for our work with individuals and reducing this would negatively impact on the success of positive outcomes. We make effective use of information technology, minimising use of paper wherever possible.



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

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or *too affected* by
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