

TIME FOR CHANGE

Fighting for health equality in 2023



**MENCAP
MATTERS**

Supporter magazine April 2023



mencap.org.uk/matters



WELCOME!

I'm Nige, a Mencap Myth Buster and part of The Oliver McGowan Mandatory Training programme. I was moved to be a trainer because it was started by Oliver's mum, Paula (see page 3). Oliver was given medication that he didn't want. His parents didn't want Oliver to take it either. Sadly, Oliver died and that shouldn't have happened. He was only 18.

People with a leaning disability and autism shouldn't be ignored like that. Everyone should be treated equally because everyone's life matters. That's why I'm going to train staff who work in hospitals. Mencap tells me that you helped to support all this, so it's a big thumbs up from me to you. Thank you!

Nigel Smith

BREAKING DOWN THE BARRIERS FOR HAPPIER, HEALTHIER LIVES

In your spring edition, we're celebrating the successes you've helped make possible in tackling health inequality for people with a learning disability.

With you, we're fighting to prevent avoidable deaths, looking out for people in crisis with the soaring cost of living, and making sure that the vulnerable don't miss out on vital health checks. **We cannot thank you enough for your ongoing support**, but much more still needs to change in the health and social care system.

People with a learning disability continue to face inequalities daily, so 2023 is time for transformation. With your support, we promise not to rest until the UK is the best place for people with a learning disability to live.

About our cover star Heidi

Crowter: "I'm a passionate activist, campaigner and wife to my husband James. I made history in 2021 by being the first person with Down's Syndrome to spearhead a national campaign to try and change the current laws surrounding people like us."

DEMANDING GOVERNMENT ACTS TO SAVE LIVES

Your support is helping to prevent avoidable deaths by tackling health inequality.

For 15 years Mencap has campaigned for change, so that people with a learning disability are treated fairly and equally by our healthcare system.

Working with campaigner and bereaved parent Paula McGowan OBE, Mencap has successfully secured government agreement to mandatory training for healthcare professionals. This will mean all health and care workers will better understand people with a learning disability and autism to meet their needs. A huge step forward, but the work must continue to make sure this training is rolled out.

About this training

The Oliver McGowan Mandatory Training was co-created by trainers with lived experience of learning disability and autism. It's named after Oliver McGowan, whose avoidable death shone a light on the training need for health and social care staff.

A shocking fact

People with a learning disability are 3 times more likely to die from causes considered treatable.



"My sister, Diana, died of asphyxia in a hospital bed, alone, neglected and in such a dreadful way. I want to do all I can to ensure that no other family has to go through what we have."

Dame Carolyn Fairbairn, Mencap's Chair of Trustees, whose sister, Diana, had a learning disability and cerebral palsy

Thanks to your kind donations, we can keep on campaigning for good quality, timely healthcare, and help bereaved families fight for health equality.



NO ONE SHOULD BE PRICED OUT AND FORGOTTEN

The cost of living crisis can cause so much distress, mentally and physically. For people with a learning disability on lower incomes and with higher outgoings the consequences can be devastating.

People with a learning disability have many additional expenses, including paying more for medication, energy and transport. With costs spiralling, people's health is suffering badly.

Over a third of people with a learning disability have skipped a meal to save money, with many resorting to using a foodbank. And **almost 5** in 10 hadn't put the heating on, even when cold.

Your incredible support has helped Mencap to:



Launch a cost of living hub for information and advice to support on food, energy and money



Lobby for legislation to stop councils taking cost of living payments to pay for social care



Be part of a campaign to secure a rise in benefits in line with inflation

Benefits shouldn't be spent on social care

We have been calling on the government to raise the Minimum Income Guarantee in line with inflation. In February we were successful with this. But more needs to be done to prevent people with a learning disability who are on benefits and receive social care from devastating income cuts. Many pay towards essential care from their own meagre benefit allowance.

The government sets out a minimum amount that councils need to leave care users with. This is just £74 a week for single people under 25.

This is a disgrace. How are people meant to eat well? Heat their homes? Or access a gym or sport activities for a healthy lifestyle?



“The future feels so bleak for us.”

MARY AND NIMALI’S STORY

Mary is a full-time carer for her adult daughter, Nimali, who has a learning disability. A year ago, Nimali had never contributed towards her social care. Then, the family received a letter from their local council informing them of a new monthly charge of £84.02.

“I was told it was for social care contributions and that I shouldn’t have expected it to be free forever.”

Nimali’s current social care package is minimal. “It covers just 2 days at a support centre, and these are paid out of her disability benefit allowance,” adds Mary. “Attending the centre is Nimali’s only meaningful social interaction outside of home. Although she struggles to make friends, she

enjoys doing Pilates, dancing and art projects. “It also gives me some much-needed respite.”

“My husband and I live off a state pension and we’re increasingly worried about our finances – sometimes we use torches instead of turning on the lights in our house in an attempt to save money. Social care costs are only going to go up, and I worry endlessly that things are only going to get worse for Nimali.”

Donations from wonderful people like you means Mencap can be there for those struggling with the cost of living crisis.

GETTING TO THE HEART OF THE ISSUES

On 12th April we will be holding a round table summit to talk about how we can eradicate health inequalities for people with a learning disability. There has been progress recently, like the introduction of the Oliver McGowan Mandatory training, but we want to do more. We are delighted to be joined by our patron Her Royal Highness, the Duchess of Edinburgh; Amanda Pritchard, CEO of NHS England, Professor Sir Michael Marmot and Paula McGowan.



WHY THE LEARNING DISABILITY REGISTER MATTERS

People with a learning disability struggle to access the healthcare they need, when they need it. People like Jason.

Falling through the gaps in the system

Jason was diagnosed with a learning disability at 12. Now in his 40s, Jason is in supported living and finds it difficult to express himself, especially when unwell. That's why his annual health check from his GP surgery is vital. Jason's father, Michael, was shocked to find his son had been removed from the learning disability register out of the blue, meaning no more automatic care.

Michael called our Helpline in England, which is fully funded by the donations we receive. We gave him the facts he needed to help Jason get back on the register. This was no easy task for lack of understanding at the surgery. Jason will now receive his essential checks, as well as priority for vaccines and boosters.

What is the learning disability register?

A list of all the people with a learning disability that the GP surgery looks after.

It helps doctors and healthcare staff know what extra support is needed.

You can ask to be added to the register at your GP surgery.

Spreading the word about the register

Not enough people with a learning disability are on the register, especially in Black and Asian communities. We've been working hard to build awareness of it.

20,000 new people have now joined the register (2020–2021)

Thanks to your support, we were able to work alongside community groups to produce resources in different languages, use digital advertising in pharmacies and promote the register in GP surgeries.

#ListenToUs

The mental health needs of people with a learning disability are being ignored. This must stop now, says Kathy.

Kathy, 76, has a learning disability and has struggled with her mental health for decades. She campaigns to get the right services in place for people like her.

“Raising awareness of mental health issues is very important to me. It can be frustrating when the waiting lists are too long for people who need help quickly and this can lead to a crisis. It’s important that these appointments are done face to face.”

“I want to get the message out there that mental health professionals need to be trained to support people with a learning disability. I’m just as good as anybody else and I deserve to have my rights.”

Not enough support. Fewer services. Social isolation and loneliness.

This is all damaging to mental health.



people with a learning disability say they experience issues with their mental health



don't know where they can go for support



families or carers say their loved one always or very often feels sad

Kind donations from people like you means Mencap is able to influence policymakers, so they can't ignore the mental health needs of people with a learning disability.

BRENDAN'S BEEN FUNDRAISING

Brendan, a Mencap Myth Buster, became depressed during the pandemic and is still dealing with the repercussions. Mencap has been supporting him to achieve his goal of giving everyone with a learning disability the same opportunities he has had. By fundraising to buy disability equipment for his old school in Zimbabwe, where he used to live.

“Doing the fundraising helps my mental health too, as I meet up with people. I’m looking for more ways to fundraise and more people to work with me. I’d like to do a disco next.”

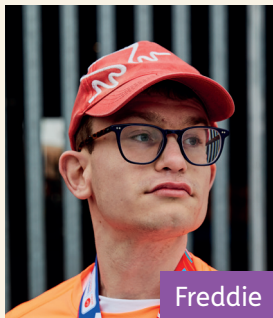
DATES FOR YOUR DIARY

TCS London Marathon

23 April 2023

Go #teammencap

162 amazing Mencap supporters, including 4 people with a learning disability, will be taking on the ultimate challenge – running 26.2 miles around our iconic capital. That includes Freddie Latham, a Mencap Myth Buster. Why not cheer them on? And why not sign up to the next event? **For more, just go to: mencap.org.uk/events**



Learning Disability Week

19–25 June 2023

Smashing stigma, stopping discrimination

Learning Disability Week is all about making sure the world hears what life is like with a learning disability. This year, we want to show how people with a learning disability can be better supported into employment. Our lunch-and-learn sessions with UK businesses will share tips on making the workplace and culture more inclusive, including small adjustments for a big difference.

If your organisation would like to know more, just email:
community.fundraising@mencap.org.uk

PLEASE DONATE TODAY

By giving now, you'll be supporting Mencap to continue our work. It's not an easy battle but, if we work together, more urgent change is possible in 2023, so people with a learning disability can lead happy, healthy lives.

How to give

You can use the donation form in your pack, scan this QR Code or go to **mencap.org.uk/matters**. Thank you!

