



MENCAP MANIFESTO

2024

INTRODUCTION

Dame Carolyn Fairbairn, Chair of Mencap, and Ismail Kaji, Parliamentary & Government Engagement Officer

Every person with a learning disability should have the right to live a happy and healthy life the way they choose. And while there has been some progress, the learning disability community continue to face barriers and inequalities in their day to day lives and when accessing public services. Some of this is due to negative stereotyping and the stigma attached to learning disability, but some stems from institutional barriers.

Mencap's goal is to make the UK the best place in the world for people with a learning disability to lead happy and healthy lives.

The next UK government must put people with a learning disability at the heart of their plans for change. The inequalities are recognised, the barriers and problems have been identified, and many of the solutions are known. It is for the next UK government to work with people with a learning disability, their supporters and organisations, to deliver change.

We hope that all the political parties will heed this call and commit to working with us and people with a learning disability.

Our manifesto outlines some of the key issues facing people with a learning disability. It is far from a comprehensive list, but committing to tackling these would make a huge difference.



We encourage people with a learning disability and their friends and family to utilise this manifesto in their own way, making it a meaningful and relevant tool for them to engage with their candidates in the forthcoming election. Please speak out - conversations with politicians can lead to great things and people with a learning disability should be heard so that the future can be brighter. Everyone stands to benefit.

Devolution Statement

Whilst we recognise that many of the issues highlighted in our manifesto are devolved in Scotland, Wales and Northern Ireland, we believe it is important for political parties across the whole UK to listen to the voices of people with a learning disability and their family and carers.

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Easy read

[Easy read version here](#)



SOCIAL CARE MARY & NIMALI

“My name is Mary. I’m 69 and for over 30 years I have been a full-time carer for my daughter, Nimali, 42. Nimali has a learning disability and undiagnosed autism. She is highly vulnerable.

Back in February 2022, her father and I received a letter out of the blue from the council informing us of a new charge of £84 a month, despite never paying for our daughter’s social care package before. It’s since gone up another £13 a month.

I was obviously distressed when I first heard, and when I called the council to query the charges I was told the extra costs were to pay ‘social care contributions’ and that ‘**I shouldn’t have expected [Nimali’s care] to be free forever.**’

Nimali’s current social care package is minimal. It covers 2 days at a support centre and 6 hours out in the community twice a month, paid out of her disability benefit allowance. Attending the centre is Nimali’s only meaningful social interaction outside home. Although she struggles to make friends, she enjoys pilates, dancing and art projects. It also gives us much-needed respite.

Despite doing all we can to reduce costs since the charges came in, we’re increasingly worried about our finances; **there is no room for more cuts, we’re so scared of the costs.** We have fitted solar lights in every room except Nimali’s and use torches instead of turning on the lights.

The nature of Nimali’s learning disability means she’s very particular about her routine. She wouldn’t understand the changes we need to make around things like energy usage or

the types of foods we can buy and would likely become distressed at the change. The normal tweaks other people can make in their homes to cut costs are much harder to make. We go without ourselves so Nimali can keep her usual routine; only turning the heating on in her room.

Our other daughters **constantly worry** because of our age and pre-existing health conditions. They worry about one of us falling down the stairs because we can’t see properly in the dark, or about us going without heating.

I was receiving Carer’s Allowance, but that stopped when I reached retirement age and was replaced with a pension of £170 a week. When my husband retired in 2018, my income reduced significantly. There’s a misconception that you have more money coming in when you retire, the reality is that many **families – and especially carers - have a lot less.**

We’ve received very little financial support. As we’re getting older, it’s hard for us to walk with Nimali – who cannot go anywhere alone – but our request for the council to help fund an essential walking machine was refused. We had to resort to borrowing money for a treadmill and pay it back in instalments.

Social care costs are only going to go up, not down. **I feel let down by the council and I worry endlessly** that things are only going to get worse for Nimali. I know we also need to make plans for after we’re gone, but with the state of social care being as it is, it’s too heart-breaking to think about Nimali’s future without us. We’ve done everything for her, her whole life.

Families should not be in this position. **We need more support, and we want to understand what is happening with social care.”**

“THE FUTURE FEELS
BLEAK FOR US.
WE’RE TERRIFIED.”



SOCIAL CARE

Many people with a learning disability rely on social care for personal care, to access the community, employment, and live their lives the way they want. The Care Act 2014 in England provides the legislative framework for social care. However, the social care system is in crisis due to chronic underfunding, with a high workforce turnover. This is leaving people with a learning disability with needs unmet. This means that many people with a learning disability cannot access the care and support they need. The next UK government must commit to fixing social care as a priority.

Adequately fund social care

Social care is severely underfunded. There is wide acknowledgement that significant additional funding is required for the sector to meet demand. The Health Foundation's recent analysis suggests that in England £8.3bn in additional funding is required by 2032/33 to simply meet future demand¹. Failing to adequately fund social care, in both the immediate and long-term, risks local authorities being unable to meet the needs of people with a learning disability.

Social care must be seen and treated as a crucial piece of the nation's infrastructure and given the parity of esteem with the NHS. An adequately funded social care system will boost the quality of life of many people with a learning disability and have wider economic benefits².

Remove social care charging

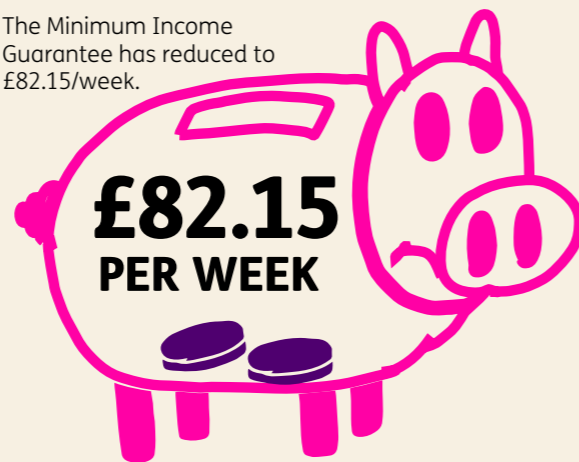
Social care should be free at the point of need. But the reality is many people with a learning disability are forced to pay towards their social care. Between 2021-2023 we have seen care charges levied against working age disabled

adults increase by £66m as councils attempt to generate more income to offset their financial pressures.



Many councils have raised additional revenue by increasing charging to the maximum allowed under the Minimum Income Guarantee (MIG) which, in England, is as little as £87.65 per week for disabled people between 18 and 25³. This MIG is the minimum amount of money a local authority is required to leave social care users with. These charges

The Minimum Income Guarantee has reduced to £82.15/week.



mean many people are simply not being left with enough to live on, especially those whose only income are benefits. We are also seeing local authorities reducing the scope of the money that people are allowed to keep after social care charges have been levied to pay for the extra costs of their disability, known as the Disability Related Expenditure.

Social care charging should be removed at the earliest possible opportunity. It is not right that those people with a learning disability who cannot work, and rely on benefits as their only source of income, are charged for accessing social care support.



SOCIAL CARE ASKS

Immediate additional funding to stabilise the social care sector and commit to a long-term funding settlement.

Remove social care charging for working-aged disabled adults (the Minimum Income Guarantee and Disability Related Expenditure).

A minimum salary for social care workers equivalent to band 3 of the NHS pay scale and a cap on agency charging.

A National Long-Term Plan for the social care workforce

Tackle the social care workforce crisis

The sector faces a recruitment and retention crisis with around 152,000 vacancies in England alone⁶. First and foremost, the workforce needs to be rewarded adequately. Our [Why We Care report](#) shines a light on the determination of our colleagues to deliver care and support and the toil this can take on them. It shows in stark clarity how the sector cannot keep up with wage increases in other sectors, including the NHS, leading to staff leaving (sometimes reluctantly) and those who stay being forced to work up to 70/80 hours per week to fill gaps risking detriment to their wellbeing and mental health.

The next UK government must address at the earliest opportunity the recruitment and retention crisis facing the social care workforce. Action on increasing pay and other structural issues must be front of centre of any social care reforms.

HOMES NOT HOSPITALS

LEO & STEPHEN

“My son Stephen is 29, he has a learning disability and severe autism. The thing that hinders him is his speech, as well as severe challenging behaviour, whereby he self-harms.

In 2012, he was sectioned and detained under the Mental Health Act. **For 7 long years I fought to get Stephen released.**

During that time, he was regularly given anti-psychotic drugs, **I was told the amount he had could have killed a horse. He had a mini-stroke due to the amount of drugs that he was taking.** He would dribble like a baby, his clothes were soaked from dribbling.

He was held down on the floor and put into a straightjacket, for up to 14 hours a day. He had numerous broken bones, all over his body. They didn't bath or shower him for 6 whole months. He went in at 14 stone, and he came out at 7.5 stone.

It was the most shocking situation as a mother, knowing I couldn't protect him. It was horrible. I love my children with all my heart, I would die for them. Nothing will ever undo the years of horror my family have endured trying to get the appropriate support for Stephen in the community.

The Mental Health Act protects institutions; they do not protect people like my son who don't have a mental health diagnosis – it abuses human rights - it's infuriating, it's disgusting.

I have been campaigning alongside Mencap to get the government to urgently reform the outdated mental health law. In October 2023 I delivered an open letter signed by 18,234 people to try and make this change. It was

very emotional handing in the petition. Right now, I want to speak up for those who are not able to themselves – whether that's people being wrongly detained in units or other families going through the same nightmare - who have been silenced or fear any step out of line could jeopardise their loved ones being released.

We need to help shape the future of every child like mine with a learning disability and/or autism in this country who has been or is at risk of being inappropriately detained in mental health hospitals.

I will keep campaigning alongside people with a learning disability and autistic people and their families until we see the law changed.”



“IT WAS THE MOST SHOCKING SITUATION AS A MOTHER, KNOWING I COULDN'T PROTECT HIM.”





HOMES NOT HOSPITALS

There are over 2,000 people with a learning disability and/ or autistic people currently locked away in mental health hospitals in England⁸. Renewed commitment is needed to help stop the flow of people into these settings as well as ensure the timely discharge of people back into their communities. The NHS Long Term Plan target to halve the number of people with a learning disability and/ or autism by March 2024⁷, compared to 2015 levels, is on track to be missed at the time of publication. A renewed programme of work is required to deliver the change people with a learning disability and autistic people and their families have long been calling for.

Reform the Mental Health Act

Reforming the Mental Health Act 1983 must be a priority for the next UK government. People with a learning disability and/ or autistic people

can currently be sectioned under the Mental Health Act even if they don't have a mental health condition. This is wrong as people can end up detained in a mental health hospital just because there is a lack of the right support in the community, not because they need inpatient mental health treatment. This must change. Alongside this, we want to see the provision around community care bolstered through strengthened duties on commissioners to provide the right person-centred community support for people with a learning disability and/ or autistic people.

Invest in sufficient community support for people with a learning disability and/ or autistic people

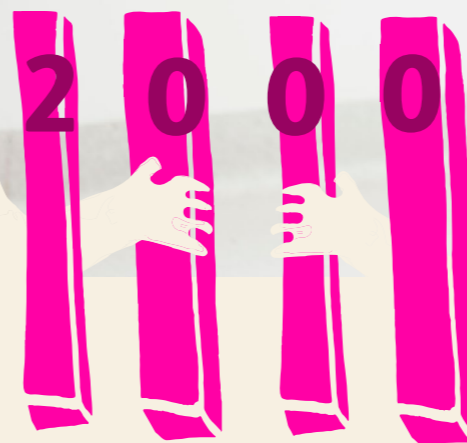
Many people with a learning disability and autistic people who are in mental health hospitals are there due to failings in their community support. There must be adequate investment in social care, suitable housing, and health and social care staff in the community with the right skills and training. This will ensure that people with a learning disability and/ or autistic people who have behaviours that can be described as challenging, get the support they need to live happy and healthy lives in their community.

Systemic change

The next UK government must learn lessons from past programmes that haven't delivered the change promised. A strengthened programme must have a focus on early intervention and prevention and the use of pooled budgets and grant funding as well as a range of other measures to remove the perverse financial incentives in the health and care system which encourage a reliance on



Over **2,000** people with a learning disability and/ or autistic people are currently **locked away** in mental health hospitals:



inpatient units. We know, and the data shows, that much more must be done to end the inappropriate detention and unacceptable length of stays in mental health hospitals that people with a learning disability and/ or autistic people are experiencing. The next UK government must show the political will to drive forward change through the health and social care system.

HOMES NOT HOSPITALS ASKS

Reform the Mental Health Act including ensuring people cannot be detained in mental health hospitals solely on the basis of having a learning disability or autism without a co-occurring mental health condition.

Invest in the right community support to stop the inappropriate detention of people with a learning disability and autistic people.

Update and strengthen the Building the Right Support Action Plan and national targets to ensure that tackling this human rights issue continues to be an urgent priority.

HEALTHCARE NIGE'S STORY

"I'm Nige, I'm supported by Midland Mencap in a house share and enjoy an independent life. I am also on the board of Trustees for Midland Mencap. I love working in the community. I work in a charity shop, it gets the mind going, it's better than staying at home doing nothing. I'm a Mencap Myth Buster too. I want to show that with the right support people with a learning disability can do things for themselves.

I love making people around me laugh. **But I am serious about putting things in the right place for people with a learning disability and/or autism when they go to the doctor's and hospital. Something has got to be done.**

My experience is that I have had bowel cancer. At first I thought I just had an infection. Then, I was just told I had cancer and given lots of leaflets to read that I did not understand. I had to rely on my support staff to help me understand. For me it's much better to talk to someone and get the support at the hospital, it should have been explained to me in person at the time.

I wasn't allowed to bring someone with me to my first screening appointment. I was by myself, and I was worried because I thought I might die alone. For me it's very, very good to get support to go to the hospital to get the treatment. My support staff were able to come with me for my future appointments and treatments after we spoke to hospital staff. But it was wrong that I was alone at first, even though it was during COVID.

After having 8 lots of treatment my bowel cancer is under control, and I now have regular check-ups, but I am anxious about my health.

I worry about minor things as I think they might be a sign of my cancer returning. I still think 'have I got cancer again? Is it properly cured?'. I wasn't offered a learning disability nurse during my treatment. I never spoke to one and I've never seen one since, even though I am still nervous at my check-ups. I feel the doctors don't think I need one, or they don't know as it has never been mentioned.

I've been told there's less of a chance of it returning after 1 year, even less after 3 years and even less again after 5 years, but you don't see inside your stomach. Will it come back the size of a fingernail or a football? Explaining it like that would help me understand it. I think there should be a model dummy to show what the issue is. I don't mean an Action Man, but a dummy to show you inside or outside what is wrong, and if it's fading, take it away.

When you go to a hospital, I think the most important thing is the hospital passport. You should take it every time you go to the hospital, it has information about things you might find difficult in the hospital environment, the reasonable adjustments or support you need and how you communicate. I think that sometimes hospital staff are not interested in it because they want to get through to the next job. **They're so busy, but we need a bit more extra time.**

I was moved by the Oliver McGowan case and wanted to do something. **I worry about people with a learning disability not being able to understand** and to make sure what happened to Oliver doesn't happen to anybody else. So I have become a trainer for health and social care professionals, helping improve understanding of people with a learning disability for better care. I love doing the training to help people, I speak about what I've been through. **Some staff do need to learn a lot."**

"I LOVE MAKING PEOPLE AROUND ME LAUGH. BUT I AM SERIOUS ABOUT PUTTING THINGS IN THE RIGHT PLACE FOR PEOPLE WITH A LEARNING DISABILITY AND/OR AUTISM WHEN THEY GO TO THE DOCTOR'S AND HOSPITAL.

SOMETHING HAS GOT TO BE DONE."



HEALTHCARE

People with a learning disability continue to face serious health inequalities and barriers to accessing care, including: a lack of understanding of learning disability, a lack of systems to help staff recognise people's learning disability and their needs for support, inaccessible information and difficulties making reasonable adjustments, and finally, scarce availability of specialist support such as learning disability nurses. Research shows that the people from ethnic minority backgrounds can experience even more barriers to accessing care.

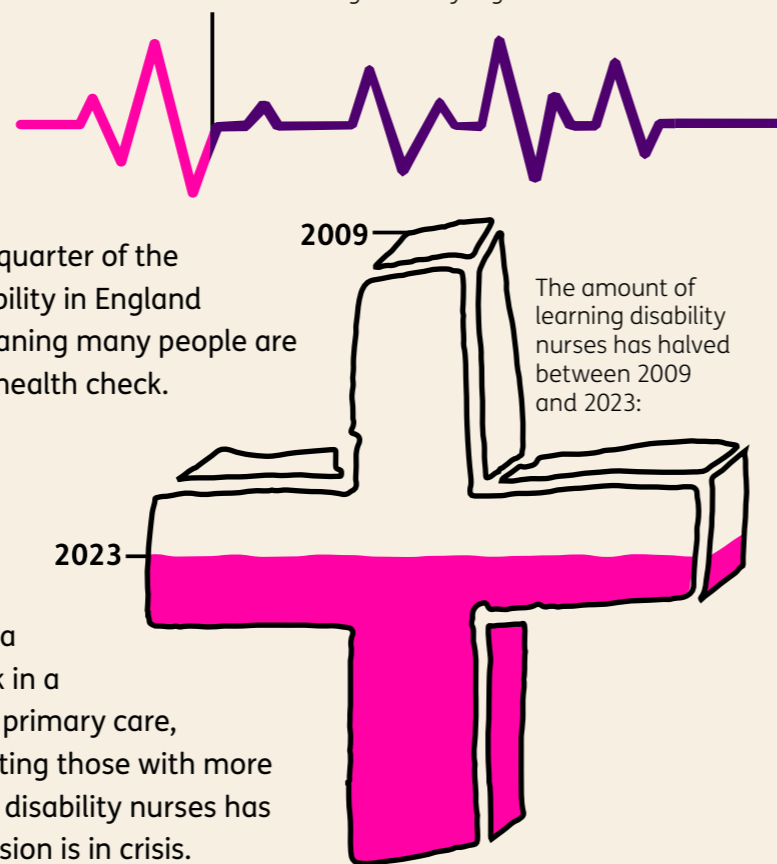
Men and woman with a learning disability die earlier than the general population⁹



Increase the number of people with a learning disability on the GP learning disability register

Annual health checks, provided by GPs, are crucial in helping people with a learning disability live a healthy life as well as manage existing or diagnose new conditions. Less than a quarter of the estimated 1.3 million people with a learning disability in England are on their GPs learning disability register¹⁰, meaning many people are missing out on vital support including an annual health check.

Less than 1/4 of people with a learning disability are on their GPs learning disability register:



Train and retain more learning disability nurses

Learning disability nurses are key to ensuring equality of access and treatment for people with a learning disability. Learning disability nurses work in a variety of roles, including acute hospital settings, primary care, community learning disability teams, and supporting those with more complex needs. However, the number of learning disability nurses has halved between 2009 and 2023¹¹, and the profession is in crisis.

Support the rollout of the The Oliver McGowan Mandatory Training on Learning Disability and Autism

Mencap has started rolling out Tier 2 training in England, however support from the next UK government is needed to ensure the training has the intended impact. The next UK government must commit to a long-term spending period to enable health and social care employers to roll out the training as well as provide an opportunity to create employment opportunities for people with a learning disability as co-trainers.

HEALTH ASKS

Work with NHS England to increase the number of people with a learning disability on the learning disability register, ensuring more people receive an annual health check and a health action plan.

Commit to funding the roll out of The Oliver McGowan Mandatory Training on Learning Disability and Autism across health and social care including support from the Department for Work and Pensions (DWP) on enabling the participation of people with a learning disability and/ or autism as co-trainers.

Ensure adequate resources at both national and local level for the successful roll out and desired impact of initiatives designed to combat health inequality for people with a learning disability, including the Reasonable Adjustment Flag and the revised Accessible Information Standard.

Implement recommendations of the Race Observatory, Health Services Safety Investigations Body¹² and Learning from Lives and Deaths of People with a Learning Disability report¹³ to tackle avoidable deaths of people with a learning disability.

Increasing the number of learning disability nurses working across the NHS, ensuring access to specialist support when needed, particularly within secondary care.



EMPLOYMENT NIAZ'S STORY

Niaz from London is autistic and has a learning disability and it took him more than 60 job applications and various job trials and placements before he landed a job as a retail assistant at Curry's.

Niaz spent a lot of time in hospital prior to the COVID lockdown which further effected his physical and mental health. Niaz had tried to undertake a supported internship during this time but had been unable to complete his placement due to his health.

Niaz's family reached out to Mencap for help. We supported him to apply for a Freedom Pass and Personal Independence Payment, as well as helping with his housing situation, so we could then start to effectively address his employment situation.

Niaz was supported by Mencap to attend weekly job clubs where he had support in using job searching sites, writing his CV, and role-playing job interviews.

"I'm Niaz, my employment journey has been marked by the challenges of learning disability and autism, mental health struggles, and the incredible transformation brought about by the support of Employ Me, a programme run by Mencap.

Before the pandemic, my health struggles led to a lack of confidence and difficulty finding employment. My mother reached out to Mencap, and that's when my journey began.

The support plan crafted by Mencap addressed my employment needs, including writing a CV, applying for essential passes, and finding

stable housing. They focused on my mental health, crucial for engaging me in the job application process.

The result? Multiple interview offers, with Mencap providing unwavering support throughout. One of these opportunities came from Curry's, offering me a part-time paid role.

Addressing the support around me, especially concerning mental health, was the turning point. Engaging in the job application process became possible because of the holistic support provided.

I am a testament to the power of comprehensive support and the incredible impact the programme can have.

I am thriving in my new career at Curry's. I've met a lot of people and learned so much about their products. The managers are lovely and super supportive. I made some friends. We have pizzas and desserts with my team. I sold a £5000 TV! My manager was so happy with me, they gave me a hand shake and said well done. Another time, I received a thank you and a gift card to eat at the restaurant Five Guys.

The money from my new job has allowed me to save for the future. I also bought a gaming keyboard and video games and an air fryer for my mum.

I have an amazing support system at Curry's and I feel so respected. I feel like they don't care what I look like or about my disability, they know how to help me."

"AS SOON AS YOU SAY YOU HAVE A DISABILITY, THEY DECIDE YOU CAN'T DO THE JOB."



EMPLOYMENT

Mencap wants to see a future where people with a learning disability receive the right support to access and stay in work. We want employers to understand that many people with a learning disability can make a valuable contribution to the workplace when supported properly.

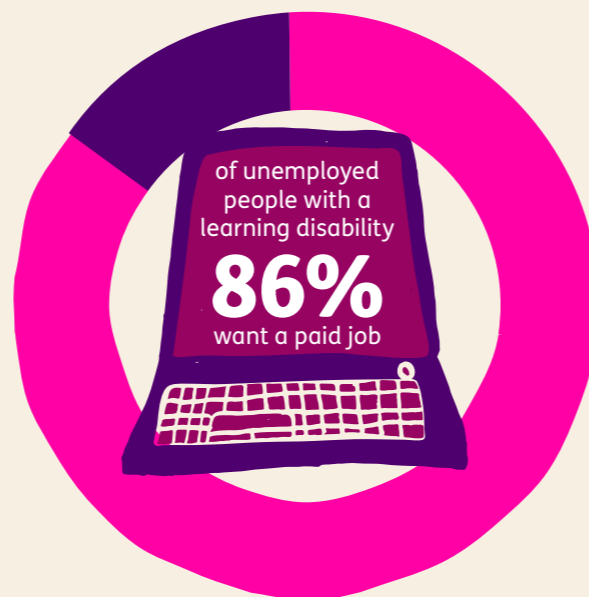
Accessing employment should be considered as a fundamental part of life for the personal, financial and social benefits it brings. However, too few people with a learning disability have the opportunity to access this. There are currently around 870,000 working-age adults with a learning disability in the UK¹⁴, but less than a third of them (26.7%) are in work¹⁵. According to the DWP most recent statistics, this is amongst the lowest employment rate experienced by people with a specific health condition or impairment¹⁶.

We know a far greater number of people with a learning disability want and can work. Research we commissioned from the National Development Team for Inclusion found

that 86% of unemployed people with a learning disability who responded to our survey wanted a paid job¹⁷.

Commit to tackling employment barriers

Current government programmes largely do not work for people with a learning disability. There are no DWP employment programmes specifically designed to support people with a learning disability into work. Mencap do not deliver the Work and Health Programme as we do not believe it is a sustainable delivery model to support people with a learning disability into work. Under the Work and Health Programme if a participant does not secure a job, the provider only receives a fraction of the funding (30% over the duration of the programme). Given the costs incurred to deliver the programme, many providers cannot take the



financial risk of supporting people farther from the labour market, including people with a learning disability.

Commit to the UK Shared Prosperity Fund long-term

The effectiveness of the UK Shared Prosperity Fund, for people with a significant disability, should be reviewed urgently and employment projects funded through UK Shared Prosperity Fund must have long-term certainty. Without this long-term commitment, there is a risk of current projects losing their acquired skills and experience or spending time on burdensome applications.

Remove benefit sanctions

Reforming the welfare system is key to empowering the majority of people with a learning disability who want to work but face systemic barriers.

Fear of being sanctioned is already preventing people with a learning disability from engaging in work-related activities¹⁸. The DWP's own research found that people who receive benefit sanctions remain on benefits longer because of being sanctioned, and when they do move into work, they move into lower paid roles¹⁹. The next UK government should commit to

exclude people with a learning disability from benefit sanctions, as well as implement safeguards, like training for Work Coaches, to prevent people with a learning disability being unfairly sanctioned.

Review the adequacy of benefits

People with a learning disability tell us that the current levels of benefits they receive are not enough to meet the basic costs of living. There has been no UK government led review of the adequacy of benefit levels since the 1960's²⁰, even though various reports have shown that current levels are inadequate and have been eroded since 2010²¹.

EMPLOYMENT ASKS

Launch a new supported employment programme for people with a learning disability, particularly for those over the age of 25, and those without an Education Health and Care Plan.

Provide long-term funding of a suitable successor to the UK Shared Prosperity Fund.

Remove people with a learning disability from the benefit sanctions regime.

Undertake or commission a review of the adequacy of benefits.

The barriers people with a learning disability face to finding and staying in employment are numerous but some of the typical barriers we see include:

- a lack of good quality support to find and stay in employment
- a lack of support to build skills
- failure by government programmes to provide the necessary adjustments required by people with a learning disability
- fears and negative attitudes from employers
- inaccessible recruitment practises
- misconceptions and a lack of understanding of what people with a learning disability can achieve with the right support



COST OF LIVING ANNETTE'S STORY

My name is Annette, and I am a learning disability caseworker at the Mencap helpline. If someone with a learning disability, their family or carer contacts the helpline with an energy or money advice enquiry, their case is assessed and if it requires casework or more in-depth support, their enquiry will be taken on by a caseworker. I specialise in offering person-centred advice and follow-on support around energy saving, benefit checks, budgeting, and housing issues.

The cost-of-living crisis is tough for everyone, but I know from the people who I speak to that **people with a learning disability and/or their families and carers have been impacted by this crisis considerably more than those without a disability.**

People with a learning disability pay a high percentage of their income to local authorities through social care charging, even if they are on benefits. The rise in the minimum income guarantee in line with inflation has alleviated some of this pressure, however it is nowhere near enough. **There needs to be a better benefits system that works for all, and that people can understand.** The government need to firmly commit to delivering in-year benefit uprating to protect those on low and fixed incomes.

Households, which include someone who has a learning disability, pay out more each month than households where no-one has a disability and often find that they are living a lower quality of life. People we encounter through the service report that they have much higher energy use for mobility, health and sensory

needs. To try and overcome higher energy bills people have informed Mencap that **they have chosen not to use their lights and instead have used head torches or candles.** People have reported only having the heating on in a chosen room, where absolutely necessary (such as their child's bedroom or main living room) and using layers of clothing and blankets to keep warm. With cost-of-living payments now ending and a failure to implement an energy social tariff, **people with a learning disability and their families/carers will continue to be faced with making these desperate choices.**

People have contacted the helpline and said that they simply cannot afford to buy food. Some tell us they do not eat every day or are eating very little. This has resulted in an upsurge in the number of people seeking advice on how to access food banks and other support in their local area to ensure they have access to regular meals. Many people with a learning disability also have special dietary requirements, which means purchasing food that is often more expensive and difficult to obtain.

Some people who call the helpline have very limited savings and have spiralling debt. **They often have to make the choice between paying bills and meeting their day to day living expenses.** With local housing allowance rates not matching private sector rental rates, we have seen a significant increase in possession orders being issued by private landlords to households that cannot afford to pay rent. A consequence of this is an increased rate of homeless applications being made to local authorities, with little housing stock available to match the increased demand. We have seen a rise in people contacting us who have mounting repair bills for their home, broken furniture, or appliances in disrepair such as fridges, freezers and washing machines that they cannot afford to repair or replace.

**“THIS CAN'T
WAIT – THE
GOVERNMENT
MUST ACT NOW.”**



On top of all these costs, people's lack of ability to bring in additional income has had a huge impact on their household budgets. People with a learning disability often find it difficult to gain employment and family members/carers are often unable to maintain stable employment because of inadequate and underfunded social care support for their family member. This has resulted in many family members becoming the main 'care giver' by default.

The issues raised have had a detrimental effect on the lives of people with a learning disability and their family members/carers. **This has led to a decline in their mental health, physical health, sense of wellbeing and overall quality of life.** Enquiries to the helpline from families needing access to respite, care and support have dramatically increased due to the impact of the cost-of-living crisis on these households.

If you have any current issues or questions, contact Mencap's Learning Disability Helpline in England by:

Phone: **0808 808 1111**

Email: helpline@mencap.org.uk
with cost of living in the subject line.

Form: [Helpline England form](#)

COST OF LIVING

Around a third of disabled people live in poverty²² and disabled households already pay, on average, an additional £975 a month to have the same standard of living as households without somebody with a disability²³. Combined with the few opportunities for people with a learning disability to increase their income through employment, their increased risk to financial exclusion and the inadequate levels of benefit that many receive, people with a learning disability have been disproportionately impacted by the cost of living crisis.

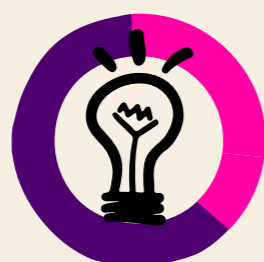


Tackling Fuel Poverty

Many people with a learning disability have higher utility requirements than non-disabled people. Mobility and hygiene needs require increased consumption of electricity, for example, to run electric wheelchairs. Some people with a learning disability also have additional health barriers, requiring medical equipment like oxygen concentrators and ventilators. Many also have important non-medical sensory needs that might involve increased use of electrical devices, or they may need their homes to be heated to a high temperature for longer because they have 24-hour carers. Despite these vital energy needs, people with a learning disability have been forced to take drastic action. In December 2023, of respondents to Mencap's Policy Shaper survey:



53% had not turned the heating on, even though they needed it



40% had not turned the lights on, even though it was dark



38% of respondents said that the crisis had affected their mental and physical health²⁴

Address long-term energy affordability challenges

Forecasts show that high energy bills are likely to remain for the rest of the decade²⁵ and that they will continue to disproportionately impact people with a learning disability due to their increased energy need. These additional costs should be met through a market-wide, progressively funded energy social tariff for disabled people which would reduce the unit cost of their energy.

Re-introduce targeted fuel poverty support for disabled people

Following recent eligibility changes, disability benefits are no longer part of the criteria for the £150 Warm Home Discount scheme²⁶. We urge the next UK government to reverse these changes by enacting the recommendation from the Energy Security and Net Zero Committee to “extend the

Warm Home Discount...especially giving consideration to those with disabilities and medical conditions.”²⁷

Continue targeted local crisis funds

In its current form, the Household Support Fund's support for disabled people has varied hugely²⁸. However, local authorities are still well-placed to administer this local crisis support and, given adequate resources, can identify people with a learning disability experiencing material hardship. All political parties must commit to long-term funding for the Household Support Fund so that it can become more accessible, more strategically targeted at disabled people in crisis and so it can provide deeper financial support.

Improve targeted support from essential services

People with a learning disability have told us that they are unhappy with the level of support they receive from their essential services, and many are unaware of the Priority Services Register. All political parties should commit to introducing a universal Priority Services Register across the water, finance, telecoms and energy sectors. Any system should be based on a ‘tell it once’ system and should enable people with a learning disability to access the tailored support they are entitled to from their essential service provider.

Access to financial services

Cost of living challenges are compounded by the myriad issues that many people with a learning disability face when trying to access financial services. We urge all political parties to commit to addressing the financial exclusion of people with a learning disability by working with the regulator to improve inclusive customer support and protect access to vital in-person banking services.

COST OF LIVING ASKS

Provide targeted energy support through existing mechanisms by reversing changes to the Warm Home Discount so it includes people in receipt of disability benefits once more.

Commit to introducing a mandatory, progressively funded energy social tariff for disabled people and their carers.

Provide long-term funding for the Household Support Fund.

Coordinate and manage the introduction of a universal Priority Services Register across essential services.

Ensure people with a learning disability have equitable access to financial services.

BULLYING

DANIELLE'S STORY*

"I use the internet to chat with other people, look at messages and photos and play games.

I have good experiences of using the internet when I get to speak to people via video calls and keep up with my friends.

I had a bad experience on Facebook. I was added to a group by someone I thought was my friend. But she did not like the guy I was friends with, so she got her friends to get pictures of me and the guy I was seeing and put them on the internet.

She was showing everyone my pictures on Facebook and they were making nasty comments about the pictures.

Afterwards they started to make threatening comments to me, saying they would send someone around to my house with a knife.

I was out with my mum and she saw the messages and reported them to the staff at my supported living house.

My mum came over and the police were called. The police came and had a chat with me.

The police found out the information for these people and they knew of some of the people involved in the bullying. They went round to their homes and spoke with them and told them they needed to stop. They also called some people as well and had a chat with them.

The police supported me to have the 'chat box' deleted and since then I have not had contact with any of the people that were involved.

I had really bad nightmares after this happened, but sharing what I was going through helped. The threatening comments were the worst and it took a long time for me to feel safe in my home.

I try to stay safe online by only speaking to people I know using their private inbox. I still have these feelings.

Before answering the door, I always look out of the window to check that it is a person I know. I also now have a video phone to be able to see who is at the door. It makes me feel safer.

I would suggest to people to be very careful who you trust online. If you think you are being bullied, share this with someone you trust and get help. And never share private information with anyone online."

*Not real name.

"IT TOOK A LONG TIME FOR ME TO FEEL SAFE IN MY HOME."

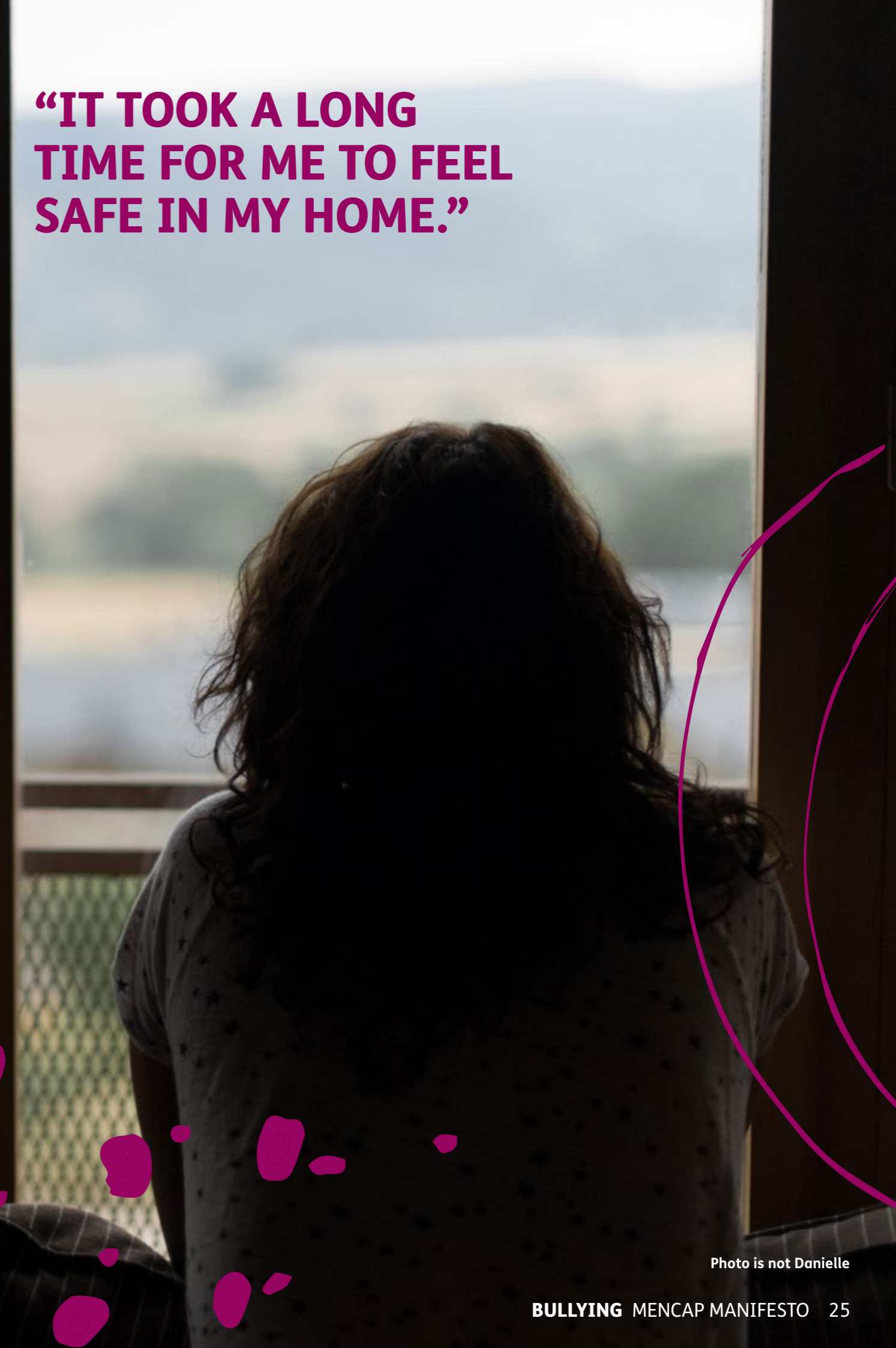


Photo is not Danielle

BULLYING AND ONLINE HARMS

People with a learning disability tend to have fewer friends, are less likely to be in a relationship, and have fewer opportunities for socialising than the general population. Research suggests that 1 in 3 young people with a learning disability spend less than 1 hour outside their home on a typical Saturday²⁹.

Being online and using social media can be a great way for people with a learning disability to tackle isolation and connect with others. However, we are increasingly finding that people with a learning disability say they feel uncomfortable online due to actual or potential abusive comments. The Office for National Statistics revealed the prevalence for online bullying was significantly higher for children with a long-term illness or disability (26%) than those without (18%)³⁰.

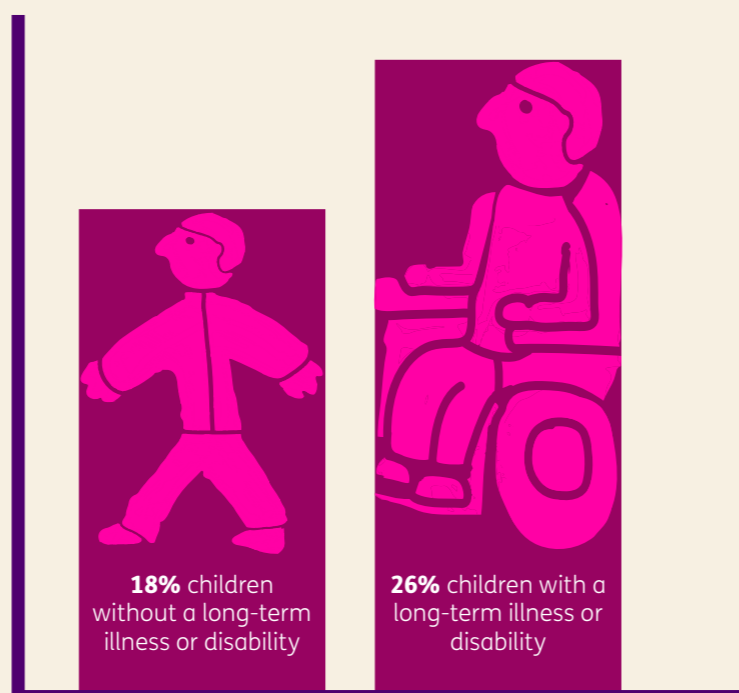
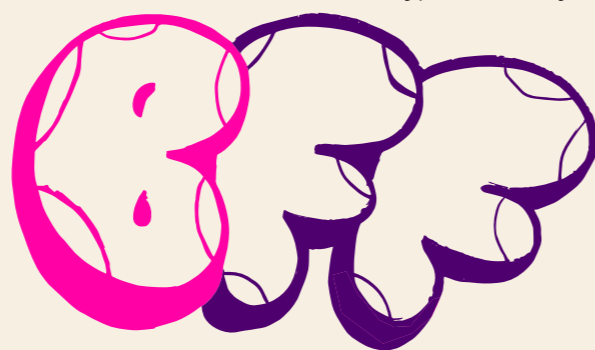
Online Safety Act implementation

We welcome many elements of the Online Safety Act which if implemented correctly should help tackle issues around the inaccessibility and inconsistency of social media platform's reporting mechanisms. Alongside the implementation of the duties in the Act, the next UK government should take a leading role in an awareness campaign on the new regulations and how people with a learning disability can best harness them to remain safe online.

Tackling stigma, discrimination and hate crime

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) provides an important external review of the UK government's action to improve the lives of disabled people and protect their human rights. It is important that the next UK government implements the recommendations of the Committee, and in particular recommendation (h) which relates to the government needing to take further action to tackle negative stereotypes or prejudice against disabled people³¹.

1 in 3 young people with a learning disability spend less than **1 hour** outside their home on a typical Saturday



Likelihood of online bullying

This recommendation also calls for “measures to address complaints of harassment and hate crime by persons with disabilities”. The Law Society has proposed a number of reforms to hate crime laws which would bring about parity between all protected characteristics. In particular, the application of ‘aggravated offence’ and ‘stir up hatred’ to disability hate crime and updating the motivation element

from ‘hostility’ to ‘hostility and prejudice’ will enable more cases to be brought to justice³². The next UK government must commit to reforming hate crime laws in line with the Law Commission’s recommendations.



BULLYING ASKS

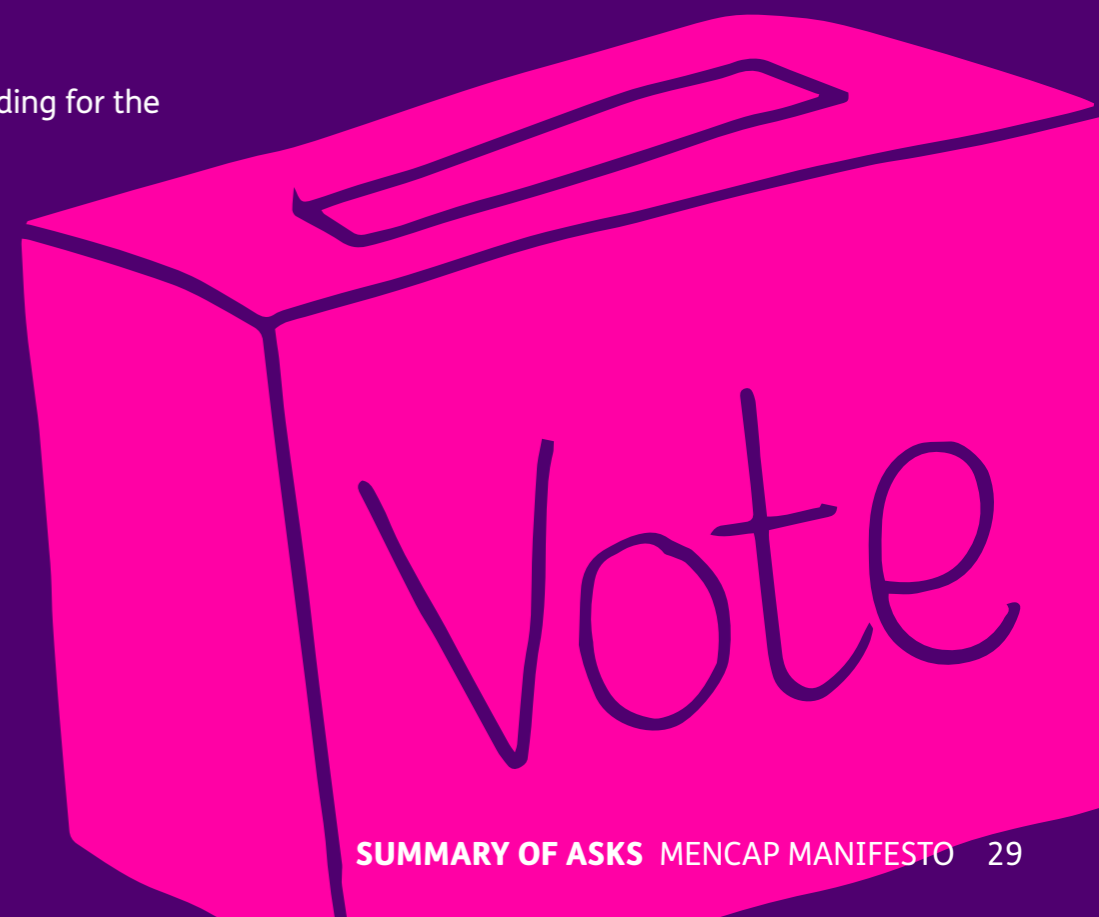
Support Ofcom on the implementation of the Online Safety Act and support an awareness campaign on the new regulations.

Implement recommendation 114(h) of the 2016 UN Convention on the Rights of Disabled People Committee Inquiry report on tackling prejudice and negative attitudes towards disabled people.

Reform hate crime laws in line with the Law Commission’s recommendations.

SUMMARY OF ASKS - ENGLAND

- 1** The next Government must provide immediate additional funding to stabilise the social care sector and commit to a long-term funding settlement.
- 2** Remove social care charging for working-aged disabled adults (the Minimum Income Guarantee charging and Disability Related Expenditure).
- 3** A minimum salary for social care workers equivalent to band 3 of the NHS pay scale and a cap on agency charging.
- 4** A National Long-Term Plan for the social care workforce.
- 5** Commit to reforming the Mental Health Act including ensuring people cannot be detained in mental health hospitals solely on the basis of having a learning disability or being autistic.
- 6** Commit to investing in the right community support to stop the inappropriate detention of people with a learning disability and autistic people.
- 7** Commit to refreshing the Building the Right Support programme.
- 8** Work with NHS England to increase the number of people with a learning disability on the learning disability register, ensuring more people receive an annual health check and a health action plan.
- 9** Ensure adequate resources at both national and local level for the successful roll out and desired impact of initiatives designed to combat health inequality for people with a learning disability, including the Reasonable Adjustment Flag and the revised Accessible Information Standard.
- 10** Implement recommendations of the Race Observatory, Health Services Safety Investigations Body and Learning from Lives and Deaths of People with a Learning Disability report to tackle avoidable deaths of people with a learning disability.
- 11** Increasing the number of learning disability nurses working across the NHS, ensuring access to specialist support when needed, particularly within secondary care.
- 12** Commit to funding the roll out of The Oliver McGowan Mandatory Training on Learning Disability and Autism across health and social care including support from the Department for Work and Pensions on enabling the recruitment of people with a learning disability and/ or autism as co-trainers.
- 13** Launch a new supported employment programme for people with a learning disability, particularly for those over the age of 25, and without an Education Health and Care Plan.
- 14** Commit to long-term funding of a suitable successor to the UK Shared Prosperity Fund. This should ensure many more people with higher support needs, including most people with a learning disability, can progress towards and into sustainable paid employment.
- 15** Remove people with a learning disability from the benefit sanctions regime.
- 16** Commit to undertaking or commissioning a review of the adequacy of benefits.
- 17** Provide targeted energy support through existing mechanisms by reversing changes to the Warm Home Discount so it includes people in receipt of disability benefits once more.
- 18** Commit to introducing a mandatory, progressively funded energy social tariff for disabled people and their carers.
- 19** Provide long-term funding for the Household Support Fund.
- 20** Commit to introducing a mandatory, progressively funded energy social tariff for disabled people and their carers.
- 21** Ensure people with a learning disability have equitable access to financial services.
- 22** Support Ofcom on the implementation of the Online Safety Act and support an awareness campaign on the new regulations.
- 23** Implement recommendation (h) of the 2017 UNCRPD report.
- 24** Reform hate crime laws in line with the Law Commission's recommendations.

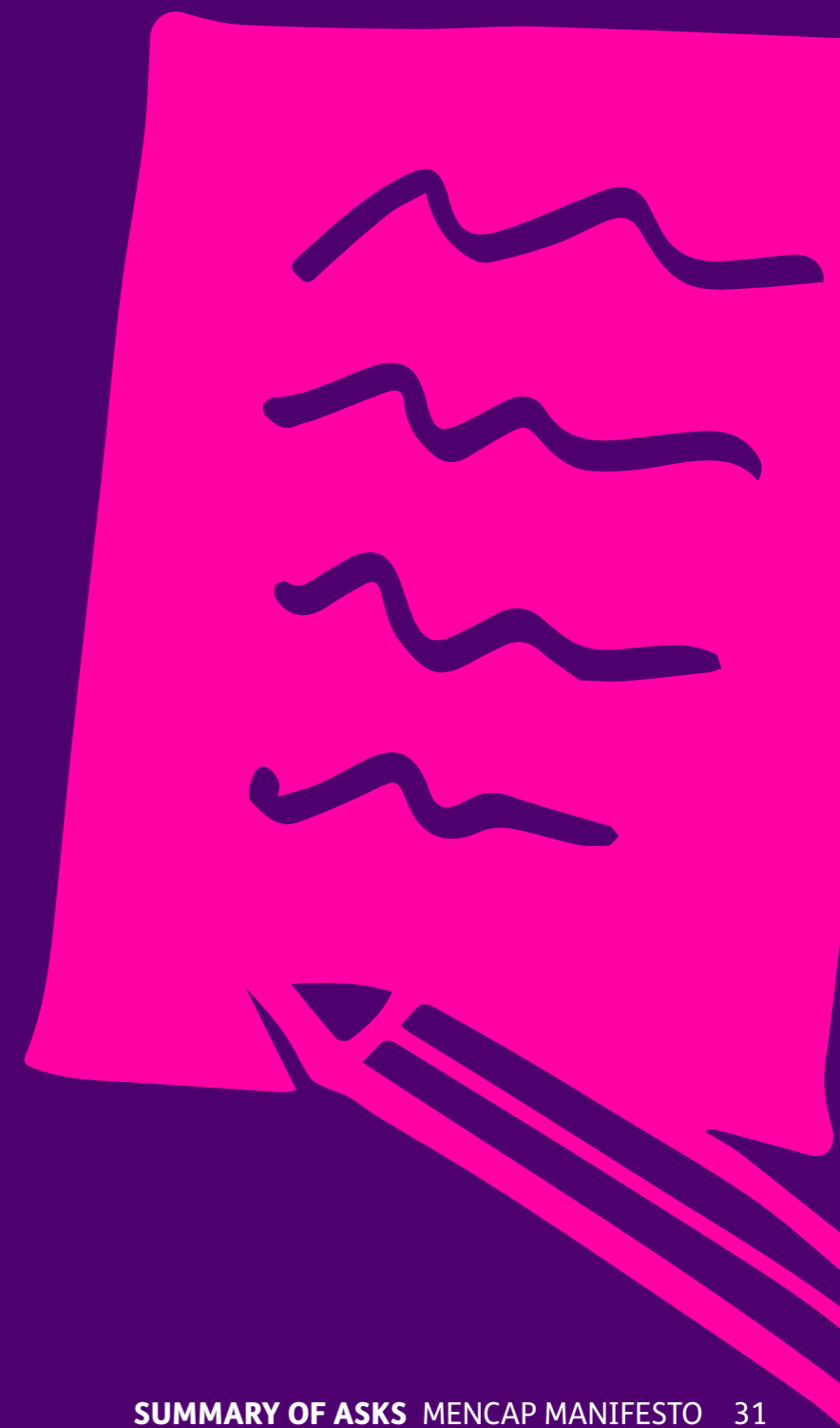


SUMMARY OF ASKS NORTHERN IRELAND

- 1 Northern Ireland, as a devolved UK region, to build sustainable government and local accountability arrangements.
- 2 Block funding of NI should be needs-based, going forward, and provision for continuous governance – which cannot be allowed to collapse in future – should be agreed and established.
- 3 Commit to long-term funding of a suitable successor to the UK Shared Prosperity Fund. This should ensure many more people with higher support needs, including most people with a learning disability, can progress towards and into sustainable paid employment.
- 4 NI government departments to give full and transparent consideration to adopting any new supported employment programmes which may be developed in GB.
- 5 Suitable community-based placements, which will replace long-stay hospital arrangements for people with a learning disability, to be identified, funded and monitored appropriately.
- 6 The next UK government must provide immediate additional funding to stabilise the social care sector and commit to a long-term funding settlement.
- 7 A minimum salary for social care workers equivalent to band 3 of the NHS pay scale and a cap on agency charging.
- 8 A National Long-Term Plan for the social care workforce.
- 9 A focus on increasing the number of learning disability nurses and on promoting healthy living for people with a learning disability.
- 10 Commit to funding the roll out of The Oliver McGowan Mandatory Training on Learning Disability and Autism across health and social care.
- 12 Remove people with a learning disability from the benefit sanctions regime.
- 13 Commit to undertaking or commissioning a review of the adequacy of benefits.
- 14 The next government should coordinate and manage the introduction of a universal Priority Services Register across essential services.
- 15 The next government to address the post-Brexit rights gaps that apply in Northern Ireland and ensure NI is fully compliant with UNCRPD.
- 16 Young children with a learning disability and their families should be identified as a priority group in key policy areas in early years, childcare, family / parenting support, child poverty, and infant mental health.
- 17 Ensure that youth work is supported by appropriate levels of sustainable investment, so that every young person with a learning disability has access to youth work services which promote social inclusion, and support their personal development.

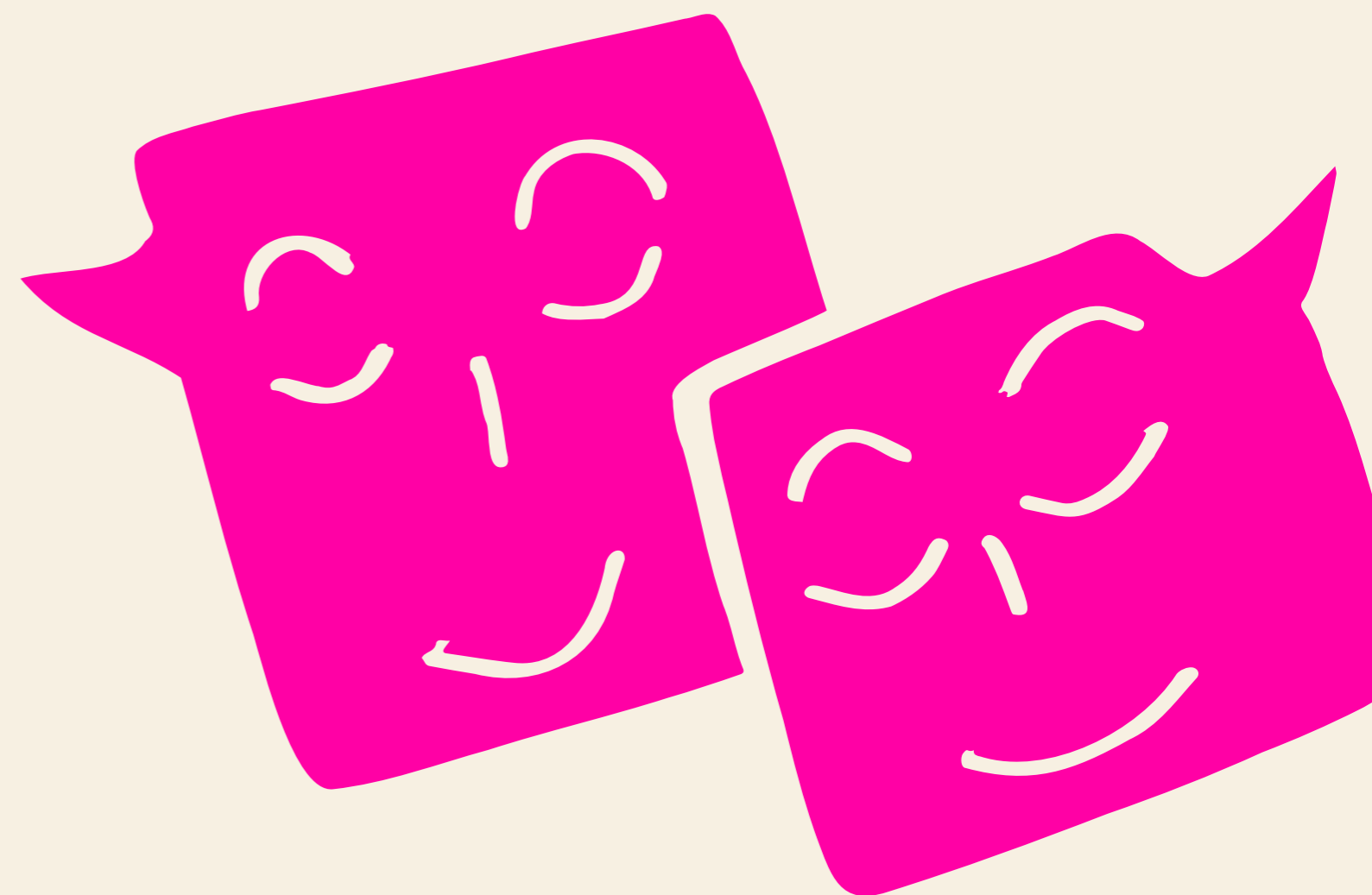
SUMMARY OF ASKS WALES

- 1 Commit to supporting Ofcom on the implementation of the Online Safety Act and support an awareness campaign on the new regulations.
- 2 Commit to introducing a mandatory, progressively funded energy social tariff for disabled people and their carers.
- 3 Remove people with a learning disability from the benefit sanctions regime.
- 4 Commit to undertaking or commissioning a review of the adequacy of benefits.
- 5 Extend Access to Work funding to allow for Job Coaching to provide pre internship preparation work and/or post internship support for people with a learning disability.
- 6 Provide long-term funding of a suitable successor to the UK Shared Prosperity Fund.
- 7 Implement recommendation (h) of the 2017 UNCRPD report.
- 8 Ensure people with a learning disability have equitable access to financial services.
- 9 Reform hate crime laws in line with the Law Commission's recommendations.



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