

# GOOD LIVES MANIFESTO 2024 BRIEFING



# GOOD LIVES MANIFESTO 2024

People with learning disabilities, families and organisations started coming together in 2020 to think about what **Good Lives** mean to them.<sup>1</sup>

This was supported by Learning Disability England, the member-led national organisation which brings together people with learning disabilities, families, organisations and paid supporters.

**The Good Lives manifesto** has been coproduced and built from a number of campaigns and actions, bringing people and organisations together on what they think are the most important priorities for the next government to take action on to make good lives possible.

This briefing document offers more information and background to the manifesto, sharing details on why each priority is important, and linking to original campaign pages.

## What we mean when we say someone has a learning disability

The **Government's definition** of says a person with learning disabilities will have:

- “a significantly reduced ability to understand new or complex information and to learn new skills, this is known as impaired intelligence
- a reduced ability to cope independently, this is known as impaired social functioning

These will have started before adulthood, with a lasting effect on development.”<sup>2</sup>

Learning Disability England works to use the Social Model of Disability.

The social model was developed by disabled people as a way of thinking about the world and how we understand disability. **Scope explain**,

“The model says that people are disabled by barriers in society, not by their impairment or difference. Barriers can be physical, like buildings not having accessible toilets. Or they can be caused by people’s attitudes to difference, like assuming disabled people can’t do certain things.

The social model helps us recognise barriers that make life harder for disabled people. Removing these barriers creates equality and offers disabled people more independence, choice and control.

Not everyone uses the social model and that’s ok. How anyone chooses to talk about their impairment is up to them.”<sup>3</sup>

The Good Lives Manifesto has 6 big aims they ask all political candidates to support.

## 1. BE A CHAMPION FOR THE RIGHTS OF ALL PEOPLE WITH LEARNING DISABILITIES, INCLUDING PEOPLE FROM MINORITY ETHNIC COMMUNITIES AND WITH HIGH SUPPORT NEEDS.

Political candidates can help by

- Putting disability equality at the heart of UK law. This means legislating to fully incorporate the UN Convention on the Rights of Persons with Disabilities (UNCRPD) into UK law.
- Committing to a new cross government strategy which puts power back in the hands of people with learning disabilities and makes sure all policy includes people with learning disabilities.
- Making sure there is strategic funding to support self-advocacy and disabled people's voice into all national and local policy. This should include plans to increase representation from people from minority ethnic communities and with high support needs.

These asks are from the [Disabled People's Manifesto](#), [Good Lives](#) and [Small Margins](#).

### Why this is important

There has been no new national policy supporting people with learning disabilities since 2009 and the closure of The National Forum and the Valuing Families Forum in 2017 has reduced people with learning disabilities and their families ability to influence and be part of policy.

People with learning disabilities experiences and life chances are significantly different to other peoples.

The [A Fair and Supportive Society](#) report demonstrates people with learning disabilities are more likely to live in poor housing environments, be in poverty and be bullied or discriminated against.<sup>4</sup> The action needed to remedy these disadvantages and premature mortality is identified as addressing the social determinants of health requiring cross government action.

The Equality and Human Rights Commission [spotlight report in 2016](#) gives further evidence of the inequity of experience.<sup>5</sup>

The UK agreed to follow the UNCRPD in 2009 but has made little progress in ensuring disabled people's rights. The UK Independent Mechanism wrote to the UNCRPD Committee in **March 2024** highlighting their **August 2023 report** which highlighted lack of implementation of the Committee's recommendations from its inquiry into the UK in 2016, which found 'grave and systematic' violations of the Convention.

The UNCRPD has been the backbone of all work around the **Good Lives Framework**.

## **Human Rights**

**Article 29 – Participation in political and public life**

### **Links to other information**

**Learning Disability Profiles: Data about people with learning disabilities**

**Exploring learning disabilities: supporting belonging | Open University**

**Funding the Gap: An investigation into the funding of self advocacy groups 2022**

**Valuing People Now: Improving outcomes for people with learning disabilities**

## 2. REFORM SOCIAL CARE SO IT MEETS THE RIGHTS OF PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES AND PROVIDES FAIR PAY FOR SOCIAL CARE WORKERS.

Political candidates can help by:

- Supporting the Social Care Future movement. The movement has a shared vision and a set of strategic actions where funding is seen as an investment in people's lives.
- 'We all want to live in the place we call home, with the people and things that we love, in communities where we look out for one another, doing what matters to us.'
- An immediate uplift to pay, funded by the government, so frontline care and supporter workers receive at least the midpoint of the hourly 'basic pay' level of NHS Band 3 staff in 2024/25.
- Make sure all people drawing on social care and their families are included in social care policy, design and delivery that focuses on person-centred and culturally competent approaches.

These asks are from [Social Care Futures](#), [Unfair to Care](#), and the [Pay Fair For Social Care campaign](#).

### Why this is important

People with learning disabilities represent a significant proportion of people drawing on social care, but the issues they and the people who support them face are rarely priorities in policy.<sup>6</sup> 46% of adults aged 18-64 getting long-term social care have a primary care need of learning disabilities (133,750 out of 292,790 people).

3% of adults aged 65+ getting long-term social care have a primary care need of learning disabilities (18,425 out of 542,545 people).

Overall, 18% of adults aged 18+ getting long-term social care have a primary care need of learning disabilities (152,715 out of 835,335 people).

There are 2.6 million voters with direct experience of drawing on or delivering social care services.

The Social Care Futures movement has brought people together to reimagine a vision for social care, that encompasses the changes we need to see for social care to be at its best. They have identified 5 key actions towards this vision and [coproduced evidence](#) of how to make these key changes.<sup>7</sup>

Social care is facing significant financial pressures. In the 2023 Sector Pulse 40% of providers reported a deficit and an increase of 350% to utility bills. Of those surveyed 85% of providers reported that government funding initiatives implemented across 2022 has no impact upon their financial sustainability.<sup>8</sup> As a result, 18% of providers offered care to fewer individuals, while 39% providers considered taking steps to close altogether.

One of the most significant cost pressures is increased the annual increases in the National Living Wage. We know that for 79% of providers that local authority fee increases did not cover this in 2023. Despite this, this manifesto calls for further increases to support workers' pay to ensure they are being properly valued.

The data in the Unfair to Care report demonstrates the Support Workers role as an NHS Band 3 equivalent in the NHS Agenda for Change Framework.<sup>9</sup> Part of this is guaranteeing they receive a 35.6% pay rise to ensure take-home pay parity with their NHS counterparts. This is a position supported by 70% of the public. In the 2023 Sector Pulse report 86% of providers cited staff pay as the key barrier to recruitment and retention of social care staff. Central government must fund this uplift.

## **Human Rights**

[Article 8: The right to a private and family life](#)

[Article 26: Habilitation and Rehabilitation](#)

## **Links to Learn More**

[Good Lives Framework: The Right Support Chapter](#)

[Social Care Futures](#)

[A brighter social care future: co-producing the evidence to make five key changes: Evidence Review \(2023\)](#)

[Time to act: a roadmap to reform care and support in England \(adass.org.uk\)](#)

[Unfair to Care: Report and Research](#)

[Pay Fair for Social Care campaign](#)

[Sector Pulse Report 2023](#)

### 3. HAVE EFFECTIVE, REASONABLY ADJUSTED HEALTH SERVICES THAT CONTRIBUTE TO BETTER HEALTH AND RAISING LIFE EXPECTANCY FOR PEOPLE WITH LEARNING DISABILITIES.

Political candidates can help by:

- Supporting investment in better reasonably adjusted preventative care, such as access to GPs, dentists and opticians, health checks and programmes to support people with learning disabilities, e.g. Postural Care.
- Calling for people with learning disabilities to be prioritised on hospital waiting lists, stopping delays that can lead to people having worse health or dying younger.
- Promoting the use of multiple formats for all written communications from the NHS, whether printed or online, including large print, Braille, easy read, and audio.
- Committing to support and promote training, awareness and culturally competent specialist support to be in place. Ensuring this is properly funded and monitored in every area so we can see if things are improving.

These asks are from the [We Can't Wait Campaign](#), [Got My Back Campaign](#), and [Your Care, Your Way Campaign](#).

#### Why this is important

The health inequalities faced by people with learning disabilities are stark and preventable. The 2023 Learning from Deaths report found people with a learning disability die younger than non-disabled people (at least 20 years younger) people. Half of people from ethnic minority backgrounds die by the age of just 34, compared to 62 for white people with learning disabilities.<sup>10</sup>

42% of the people with learning disabilities who died in 2022 died an 'avoidable' death.

Public Health England research shows every day between 30,000 to 35,000 adults with a learning disability are taking psychotropic medicines, when they do not have the health conditions the medicines are for.<sup>11</sup>

NHS Digital Health and Care of People with Learning Disabilities dataset for England 2022/23<sup>12</sup> reports that:

1) 9% of people with learning disabilities without a diagnosis of severe mental illness are taking anti-psychotic medicines (compared to 0.4% of people without learning disabilities)

2) 12% of people without a diagnosis of depression are taking anti-depressant medicines (compared to 4% of people without learning disabilities)

**Reasonable adjustments** are a legal duty and have been demonstrated to contribute to better health outcomes.<sup>13</sup>

Body Shape Protection (sometimes called Postural Care) can improve the health outcomes and reduce the need for surgery or premature death for adults with profound and multiple learning disabilities. Early intervention was **recommended by NICE guidance**.<sup>14</sup>

There are **established mechanisms** to improve health access and reduce premature death that local and national NHS organisations can continue or improve implementation of.<sup>15</sup>

## Human Rights

### Article 25 – Health

## Links to learn more

[Learning from Deaths Report: 2023](#)

[NHS Race and Health Observatory report We Deserve Better](#)

[NICE impact people with a learning disability | Reviewing the impact of our guidance | Measuring the use of NICE guidance | Into practice | What we do | About | NICE](#)

[Funding The Gap May 2022](#)

[We Can't Wait Campaign](#)

[Your Care, Your Way Campaign](#)

[STOMP Campaign \(Stop Over Medicating People\)](#)

[Got My Back Campaign](#)

[Postural care and people with learning disabilities: guidance - GOV.UK \(www.gov.uk\)](#)

[Social care staff supporting reasonable adjustments](#)

[Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities](#)



## 4. HELP PEOPLE WITH LEARNING DISABILITIES GET THE JOBS THEY WANT SUPPORTED BY A SYSTEM THAT RECOGNISES CONTRIBUTIONS NOT FORCING POVERTY.

Political candidates can help by:

- Making sure people with learning disabilities are equally included in employment support initiatives and not further disadvantaged. This includes but is not limited to:
  1. Employment and pay gap reporting.
  2. Supporting disabled people into employment.
  3. Reform of Access to Work.
  4. Reform of Disability Confident scheme.
- Working with people with learning disabilities and their supporters to remove the barriers to employment and to share what is possible
- Co-produce the benefits system that recognises everyone's right to an adequate standard of living and values individual's contribution not penalising disability.

These asks are from the [Disability Employment Charter](#), [Employment is for Everyone Campaign](#) and [Disabled Peoples Manifesto](#).

### Why this is important

The number of people with a learning disability recorded in employment has been around 6% for many years and as low as 4.8%,<sup>16</sup> but research shows as many as 86% want a paid job.<sup>17</sup>

The Supported Employment model has been used for decades to support people with learning disabilities to work, with growing evidence of its success in creating valuable workers in sustainable long-term employment. Adjustments for employing someone with a learning disability cost only £75.<sup>18</sup>

Joseph Rowntree Foundation found low-income households with a disabled person are being hit hard by the cost-of-living crisis, with almost 6 in 10 experiencing food insecurity in April/May 2023. 71% going without essentials between November and May. On average, disabled households need an additional £975 a month to have the same standard of living as non-disabled households.<sup>19</sup>

The Commission on Social Security offered evidence based actions for a system that supports disabled people fairly. This includes a Guaranteed Decent Income and looks to replace Personal Independence Payments (PIP) with a new benefit set up with disabled people.<sup>20</sup>

## **Human Rights**

[Article 27 – Work and employment](#)

[Article 28 – Adequate standard of living and social protection](#)

## **Links to learn more**

[Good Lives: Employment and Contribution](#)

[Disability Employment Charter](#)

[Employment is for Everyone Campaign](#)

[Disabled Peoples Manifesto](#)

[Scope's Disability Price Tag Report \(2023\)](#)

[Joseph Rowntree Foundation: Our social security system must support households with a disabled person to afford the essentials](#)

[Nuffield Trust: Supporting people in employment](#)

[British Association of Social Workers: Anti-poverty Spotlight](#)

[The Commission on Social Security: The Plan for a Decent Social Security System](#)

[British Association for Supported Employment: What Is Supported Employment?](#)

## 5. MAKE SURE PEOPLE WITH LEARNING DISABILITIES HAVE THE SAME ACCESS TO HOUSING OPTIONS AS THEIR NONDISABLED PEERS.

Political candidates can help by:

- Ending the use of secure hospitals as homes for people with learning disabilities and fund the right support in the community.
- Level up social housing so people with learning disabilities, alongside others have access to safe and secure accommodation.
- Make sure there are Support to Live options by:
  - Supporting national and local annual targets to build supported housing for people with learning disabilities and autistic people and publish the number and type of schemes funded.
  - Supporting reform of the rules for rent setting for housing associations in relation to Supported Housing and public subsidy. This could allow grant funding to support the development of housing needed for many people with learning disabilities and autistic people to have appropriate housing.

These asks are from the [Don't Lock Us Away Campaign](#), [Shelter England](#) and [Learning Disability and Autism Housing Network](#).

### Why this is important

12 years on from the Winterbourne View scandal, there were still 2,035 people with learning disabilities and/or autism in secure hospitals at the end of January 2024. Targets to support people to leave hospital and live in the community are being continuously missed.<sup>21</sup>

Approximately 27,000 new supported housing units are needed over the next 15 years to meet the needs of people with learning disabilities and autistic people.<sup>22</sup> 200 Lives found when taking accommodation costs into consideration, supported living was less expensive than residential care.<sup>23</sup>

Additionally the 200 Lives research found that only 25% of their participants who live in supported living reported having full housing rights, as measured by the Real Tenancy Test. A majority of people in residential care see fewer of their housing rights in practice in comparison to those in supported living.

The [My Front Door research](#) found people with learning disabilities can successfully rent their own home and make a number of recommendations to landlords about how they can better support people as tenants.

## **Human Rights**

[Article 19 – Living independently and being included in the community](#)

## **Links to Learn More**

[Good Lives: A Home](#)

[Don't Lock Us Away Campaign](#)

[Homes not hospitals: Building the Right Support update](#)

[Learning Disability and Autism Housing Network: research on projected need](#)

[200 Lives project: Evaluating supported living and residential care for adults with learning disabilities](#)

[Shelter England](#)

## 6. MAKE THIS AN ACCESSIBLE GENERAL ELECTION.

Political candidates can help by:

- Providing accessible information to constituents about your role as a public representative.
- Raising awareness about My Vote My Voice campaign which is there to help people with learning disabilities and autistic people vote.
- Joining and arranging inclusive and accessible election hustings for constituents to directly engage with you and ask questions about your party's positions, where people from minority ethnic communities are informed, invited and engaged in the hustings.

These asks are from the [My Vote My Voice](#) campaign charter.

### **Why this is important...**

People with learning disabilities represent 1.5 million people in the UK, we must be listened to. 82% of people in a survey by Dimensions felt the Government did not listen to those with a learning disability as much as it listens to other people.<sup>24</sup>

There are numerous barriers to voting for people with learning disabilities.

Following the 2010 general election, a survey found 17% of people were turned away from the polling station due to their learning disability.<sup>25</sup> Of the people who could vote, 80% reported polling stations were difficult to use and 76% struggled to find easy-read manifestos to support them to make a decision on who to vote for.

60% said that registering to vote was too hard. Since then we have seen the introduction of voter ID, creating an additional barrier when around 1 in 4 people with a learning disability aren't registered to vote.

Bradford MBC Social Workers have been working to 'Promote the Vote' since 2015 seeing consistent results.<sup>26</sup> They have found that there is a number of supported living staff believe that a lack of capacity means a lack of ability to cast a vote.

## **Human Rights**

[Article 29 – Participation in political and public life](#)

## **Links to Learn More**

[My Vote My Voice](#)

[Dimensions' Voting Research](#)

[Disabled people: political participation, House of Commons Library Research Briefing](#)

[Promote the Vote: A BASW Practice Guide | BASW](#)

## REFERENCES

- <sup>1</sup> Learning Disability England (2022) Good Lives Framework  
[https://www.learningdisabilityengland.org.uk/wp-content/uploads/2021/02/The\\_Good\\_Lives\\_Framework-9.3.22.pdf](https://www.learningdisabilityengland.org.uk/wp-content/uploads/2021/02/The_Good_Lives_Framework-9.3.22.pdf)
- <sup>2</sup> Public Health England (2020) Reasonable adjustments: A legal Duty  
<https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty>
- <sup>3</sup> Scope (undated) What is the social model?  
<https://www.scope.org.uk/about-us/social-model-of-disability/>
- <sup>4</sup> Institute of Health Equity (2018) A Fair, Supportive Society: Summary Report  
<https://www.instituteoftheequity.org/resources-reports/a-fair-supportive-society-summary-report>
- <sup>5</sup> Equality and Human Rights Commission (2016) England's most disadvantaged groups: People with learning disabilities  
[https://www.equalityhumanrights.com/sites/default/files/2021/is-england-fairer-2016-most-disadvantaged-groups-learning-disabilities\\_0.pdf](https://www.equalityhumanrights.com/sites/default/files/2021/is-england-fairer-2016-most-disadvantaged-groups-learning-disabilities_0.pdf)
- <sup>6</sup> NHS Digital (2023) Adult Social Care Activity and Finance Report, England, 2022-23  
<https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2022-23>
- <sup>7</sup> Research in Practice and Social Care Future (2023) A brighter social care future: Evidence Review  
<https://www.researchinpractice.org.uk/adults/content-pages/open-access-resources/a-brighter-social-care-future-co-producing-the-evidence-to-make-five-key-changes/>
- <sup>8</sup> HFT (2023) Sector Pulse Check 2023  
<https://www.hft.org.uk/get-involved/public-affairs-policy-and-campaigns-sector-pulse-check/>
- <sup>9</sup> Community Integrated Care (2024) Unfair to Care 2024 Report: Who Cares Wins.  
[https://c-6.net/virtualdocs/unfairtocare2024\\_a4brochure/](https://c-6.net/virtualdocs/unfairtocare2024_a4brochure/)
- <sup>10</sup> Kings College London (2023) Learning From Deaths 2023 Report: Key finding of review of lives and deaths for 2022  
<https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-takeaways.pdf>
- <sup>11</sup> NHSE (Undated) Stopping over medication of people with a learning disability, autism or both (STOMP)  
<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>
- <sup>12</sup> NHS Digital Health and Care of People with Learning Disabilities dataset for England 2022/23  
<https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2022-to-2023>
- <sup>13</sup> Public Health England (2020) Reasonable adjustments: a legal duty: Guidance  
<https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty>
- <sup>14</sup> Public Health England (2018) Postural care and people with learning disabilities: guidance  
<https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments/postural-care-and-people-with-learning-disabilities>
- <sup>15</sup> Department of Health (2008) Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities  
[https://webarchive.nationalarchives.gov.uk/ukgwa/20130105064250/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_099255](https://webarchive.nationalarchives.gov.uk/ukgwa/20130105064250/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255)
- <sup>16</sup> Nuffield Trust (2023) Supporting people in employment  
<https://www.nuffieldtrust.org.uk/resource/supporting-people-in-employment#>
- <sup>17</sup> Department of Health (2009) Valuing Employment Now: real jobs for people with learning disabilities  
[https://webarchive.nationalarchives.gov.uk/20130105061742/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_103202.pdf](https://webarchive.nationalarchives.gov.uk/20130105061742/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103202.pdf)
- <sup>18</sup> Mencap (2017) Good for business: The benefits of employing people with a learning disability  
<https://www.base-uk.org/sites/default/files/knowledgebase/Business%20case%20for%20employing%20people%20with%20a%20learning%20disability.pdf>

- <sup>19</sup>Scope (2023) Disability Price Tag 2023: the extra cost of disability  
<https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag-2023/>
- <sup>20</sup>Trust for London (2022) The Commission on Social Security: The Plan for a Decent Social Security System  
<https://trustforlondon.org.uk/research/the-commission-on-social-security-the-plan-for-a-decent-social-security-system/>
- <sup>21</sup>NHSE Digital (2024) Learning Disability Services Monthly Statistics, AT: January 2024, MHSDS: December 2023  
<https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics/at-january-2024-mhsds-december-2023>
- <sup>22</sup>Learning Disability and Autism Housing Network (2023) Supported housing for people with learning disabilities and autistic people in England  
[https://www.housinglin.org.uk/\\_assets/Resources/Housing/Support\\_materials/Reports/Supported-housing-for-people-with-learning-disabilities-and-autistic-people-in-England.pdf](https://www.housinglin.org.uk/_assets/Resources/Housing/Support_materials/Reports/Supported-housing-for-people-with-learning-disabilities-and-autistic-people-in-England.pdf)
- <sup>23</sup>Manchester Metropolitan University, NDTI, Changing Our Lives, London School of Economics (2022) Resources from 200 Lives project: Evaluating supported living and residential care for adults with learning disabilities  
<https://www.ndti.org.uk/resources/research-project/resources-from-200-lives-project-evaluating-supported-living-and-residential-care-for-adults-with-learning-disabilities>
- <sup>24</sup>Dimensions (2021) Dimensions survey highlights importance of empowering people with a learning disability and/or autism to vote  
<https://dimensions-uk.org/press-release/dimensions-survey-highlights-importance-empowering-people-learning-disability/>
- <sup>25</sup>House of Commons Library (2023) Disabled people: political participation  
<https://commonslibrary.parliament.uk/research-briefings/cbp-9718/>
- <sup>26</sup>British Association of Social Workers (2024) Promote the Vote: A BASW Practice Guide  
<https://new.basw.co.uk/policy-and-practice/resources/promote-vote-basw-practice-guide>



## MORE INFORMATION AND RESOURCES TO HELP YOU TAKE ACTION

### Good Lives Manifesto

This is a document offering more information, details on why each priority is important, and linking to original campaign pages.

### Pledge card

## YOU CAN READ MORE

Learning Disability England can help you connect to members in your area.

Contact us at [info@LDEngland.org.uk](mailto:info@LDEngland.org.uk)

### How we made this

This manifesto was made by Learning Disability England members. More than 450 people from the 680 organisation and individual members got directly involved in deciding what is most important.

You can read more here.



We would love to hear from you

[www.learningdisabilityengland.org.uk](http://www.learningdisabilityengland.org.uk)

[info@LDEngland.org.uk](mailto:info@LDEngland.org.uk)

Or call our office on 0300 1110444