

# CHAPTER 7: HEALTH FOR A GOOD LIFE

“Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence.”

Helen Keller ●

● The BILD for the Future group worked on what should be incorporated this chapter. Sessions were held at the London and Leeds Learning Disability England conferences to gather people’s views on what mattered to them. An online survey was conducted and an online meeting with professionals that work in health. There was also an online meeting for people with learning disabilities and family members.

# WE ASKED AND YOU SAID

Health is about more than clinical checks.

There are bigger barriers for some people who cannot speak up for themselves.

People with learning disabilities, families and support workers feel they are not listened to or respected by all health services.

Eating well:

- Limited access to affordable good food (even harder for people with dysphagia).

- Not having good information and help on eating well.
- A lack of accessible support to lose weight or change diet.
- Real choice on good food in shared support settings.

Exercise:

- Gyms are expensive and supports costs not covered.
- A lack of accessible information and support on exercise and different options.
- Many support staff are not confident or trained in talking about exercise and health.

- Not having local park/open spaces

#### Isolation/Loneliness:

- A lack of affordable places to meet others.
- Not having support or transport to go out.
- Social care services not valuing friendships and family.

#### Access to services:

- There are very few mental health services that offer accessible services for all.
- Many people cannot get dentists, mental health support or accessible optician appointments.

- There are many barriers to booking appointments or managing health advice as it is often inaccessible.
- People ‘get lost’ on waiting lists within complicated systems.
- There is a lack of reasonable adjustments that help people access health services.
- Diagnostic overshadowing or poor attitudes to people’s worth.
- Lack of preparation, poor experience or follow up for Annual Health Checks.
- Families and support workers feel they are often not listened to when they raise concerns about someone.

## HUMAN RIGHTS FRAMEWORK

The right to health is not explicitly stated in the European Convention on Human Rights, but it is implied by some of its articles. For example, Article 3 prohibits inhuman or degrading treatment, and Article 8 protects respect for private life, including moral and physical integrity. Regulations in the Health and Social Care Act 2008 link to the European Convention on Human Rights Articles incorporated within the Human Rights Act. These regulations can be used to take action to uphold aspects of people's human rights.

United Nations Convention on the Rights of Persons with Disabilities provides a more detailed account of the rights of disabled people in relation to health.

## ARTICLE 25 – HEALTH

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c Provide these health services as close as possible to people's own communities, including in rural areas;
- d Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

You can find more information about these rights [HERE](#)

# HUMAN RIGHTS FRAMEWORK

- e Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

### 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 (at least 20 years) than non-disabled people. The report indicated that people from minority ethnic backgrounds with learning disabilities have higher mortality rates compared to their white counterparts. This disparity is often linked to systemic inequalities in healthcare access and quality.

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

There are also serious concerns over the levels and types of medications people with learning disabilities are being prescribed. 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 generally prescribed for.

NHS Digital Health and Care of People with Learning Disabilities dataset for England 2022/23 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.

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.

Established mechanisms to improve health access and reduce premature death that local and national NHS organisations exist and should be implemented more consistently.

You can find more information about these rights [HERE](#)

# HUMAN RIGHTS FRAMEWORK

# IDEAS WE CAN WORK ON TOGETHER

We have gathered ideas of things we can work on together to improve the lives of people with learning disabilities in the areas they said are important to them and their families. Some of the initial ideas are:

- Help people understand and ask for their right for reasonable adjustments to be made to make access to health care easier and more effective.

- Investment in community services that support human connection, exercise, good eating, learning and contribution

- Support for social and family life (see the Staying Connected chapter).

- 'Good work' that is paid or unpaid.

- GPs and practices investing in Annual Health Checks and Health Action plan.

- Health services that understand people with learning disabilities and listen to them and their families and supporters.

- More accessible information and systems so people can understand and manage their health. All organisations that provide NHS or adult social care must follow the accessible information standards by law. The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support so they can communicate effectively with health and social care services.

- The NHS 10 Year plan and all reform done inclusive of people with learning disabilities and incorporating the evidence base of what reduces inequalities and ensures health equity.

# WHAT GOOD MIGHT LOOK LIKE (HOW WILL WE KNOW WE ARE ON THE RIGHT TRACK)

## Good example 1

The VIP Red Bag is an initiative designed to support people with learning disabilities and autistic individuals during medical appointments and hospital admissions. Launched in Wakefield in 2021, and now also available in Bradford. The VIP Red Bag holds all essential health and support information.

The project has been successful in improving healthcare outcomes by ensuring that important information is readily available to healthcare professionals, allowing them to provide better, more personalised care.

## GOOD Example 2

Changing Our Lives worked with Simple Stuff works to develop 'Got your Back' information and resources on Postural Care including a Postural Care passport and resources for nurses. They help everyone think about posture and protecting body shape for those who might need it most.

## Good example 3

The Josephine and Jack Project is an innovative initiative that uses life-size, anatomically accurate cloth figures named Josephine and Jack to facilitate workshops and one-on-one sessions with adults and young people with learning disabilities. These sessions cover a range of topics, including health, well-being, relationships, sex, and sexuality.

### Good example 4

The Down's Syndrome Association offers a variety of resources and activities to support the health and well-being of individuals with Down's syndrome. One of their key initiatives is the DSEngage program, which includes a range of online activity sessions. DSEngage provides free, online sessions that cater to both children and adults with Down's syndrome. The activities are designed to improve physical and mental health.

### Good example 5

Hospital Trusts can identify people with learning disabilities on waiting lists for treatment and take action to clear any backlog. Calderdale and Huddersfield NHS Foundation Trust did this as part of their work to make sure people get equitable access and outcomes.

### Good example 6

Menopause Cafés are informal gatherings where people come together to discuss menopause over tea and cake. These events aim to break the taboo surrounding menopause, increase awareness of its impact, and provide a supportive environment for sharing experiences.

### Good example 7

There are resources and information on Annual Health checks for people with learning disabilities from minority ethnic communities. Coproduced by the Race Equality Foundation and people and families from minority ethnic communities to improve awareness and increase uptake.

# WHO DO WE NEED TO ENROL/ENGAGE?

There are significant challenges facing learning disabled people in terms of having their right to health respected, protected and upheld. Some of this is attitudinal, the acceptance that people with learning disabilities die ‘avoidable deaths’ at a far higher rate than the national average is a national disgrace. That this is not a national scandal raises questions about the value places on the lives of people with learning disabilities and for that matter on the lives of those who love them.

There is a greater spotlight on the inherent discriminatory attitudes in health and social care and active awareness raising by individuals, families and organisations has placed a spotlight on some of the most egregious examples.

However, it is incumbent upon all of us, to not accept this current situation as inevitable but rather to do all we can to ensure that everyone has their right to health respected. There are supportive tools and measures such as the requirement for reasonable adjustments that should strengthen the resolve of citizens to secure their rights, if they are aware of them.

## NEXT STEPS/FIRST STEP

We need to raise our expectations of how people with learning disabilities will be treated by health and social care using existing tools and supports to strengthen our resolve and our ask. It will be important to seek allies to strengthen the argument that better is indeed possible.

### FOR HEALTH SERVICE PROVIDERS

Implement the Reasonable Adjustments Digital Flag. This is a national record developed by NHS England to ensure that individuals with disabilities receive the necessary accommodations in healthcare settings. This digital flag is part of the NHS Spine and allows health and care professionals to record, share, and view details of reasonable adjustments required for patients across

the NHS. It would help health providers better understand the reasonable adjustments required for all people with learning disabilities served.

Health provider should review manage waiting lists to ensure that people with learning disabilities are not further disadvantaged. They should consider signing up to the We Can't Wait campaign.

### FOR SERVICE PROVIDERS

Social Care providers can make sure support staff know how to help people think about what they eat and how they stay active. For some people this means organisations having good rights-based systems that support a healthy life where people may not be able to make these decisions themselves. It is important that people have access to independent advice and support. Learning Disability England offer on going hosting to work done by Sunderland People First in partnership with the University of Sheffield to create a website of self-advocacy groups in England.

## FOR GOVERNMENT

### The Good Lives

**Manifesto** We found there are not enough policies about people with a learning disability from ethnic minorities. Services do not have clear advice from government This makes it harder to make things better for people.

**The ask:** We need more policies to include good support for people with learning disabilities from ethnic minorities.

The Good Lives Manifesto there needs to be a concerted effort to prioritise those who are most at risk of having their rights and health breached. The data shows that this includes people with learning disabilities and those from minority ethnic communities most specifically.

**The ask:** The government needs to support 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.

### The Good Lives

**Manifesto** not all citizens have the same experience of health care. Some, including people with learning disabilities are more disadvantaged. This unjustifiable situation needs to be remedied proactively.

**The ask:** The government needs to ensure that people with learning disabilities need to be prioritised on hospital waiting lists, stopping delays that can lead to people having worse health and/or dying younger.

### The Good Lives

**Manifesto** The government needs to ensure the NHS meets its obligations to provide accessible information to ensure that people with learning disabilities can safely access health support and make informed decision about their health care.

**The ask:** The NHS must promote the use of multiple formats for all written communications from the NHS, whether printed or online, including large print, Braille, easy read, and audio.

### The Good Lives

**Manifesto** The government needs to ensure that the NHS has the funding required to address the fact that citizens do not enjoy a standard experience of health and social care. Health outcomes for black and minority ethnic communities are quantifiably poorer than the general population.

**The ask:** The government needs to ensure that sufficient funds are available and are committed to support and promote training, awareness and culturally competent specialist support to be in place. Ensuring this is monitored in every area so we can see if things are improving.

## FOR ALL NON-DISABLED PEOPLE

There needs to be an increasing awareness that a health service that accepts poor levels of health outcomes for some will, potentially, allow such poor outcomes for all. It is in everyone's best interest that the health and social care system works to the highest standard for all.

## FOR ALL COMMISSIONERS

Commissioners need to invest in initiatives that nurture accessible community-based supports that help people make and remain connected to friends and stay healthy and active.

Commissioners need to ensure all service specifications include explicit recognition of the service making reasonable adjustments and working positively with disabled people, particularly people from minoritised ethnic communities. This will require collecting and analysing data on who is, and importantly who isn't, accessing services.

There is an urgent need to support local GP practices to deliver high quality annual health checks and health action plans.

## FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

There is a wide array of resources available to strengthen your case for your right to health to being respected, protected and upheld, much of it in an accessible format. It would be really helpful to use and share these widely with others you may know to develop knowledge and capacity and to help people understand.

Also, if you or your group develop something please share it with LDE who may then share it to support others.