

2025 REFRESH VERSION

# THE GOOD LIVES FRAMEWORK: BUILDING CHANGE TOGETHER



# PROLOGUE

Learning Disability England (LDE) is working to build a movement where people with learning disabilities, family members, friends, paid supporters and allies come together on an equal basis, to champion positive change.

As a membership organisation, Learning Disability England wants to provide a national focal point where everyone can come to together to build a world where people with learning disabilities have every opportunity to lead their good life.

We recognise the privileged position we hold, connecting with a broad range of people, both members and non-members. Through our work we hear the lived experiences of a wide range of people, both the heartache and trauma of lives that are limited unnecessarily and equally stories of courage and fortitude. We witness the power of allyship and friendship, and of the resourcefulness of relationships forged in adversity.

This is the second edition of the Good Lives Framework. In keeping with the first edition, we want to continue the process of sharing what the people we have engaged with say they want and need to live well, and we aim to harness this collective knowledge, wisdom, energy, and activity. We will also highlight the challenges that get in the way of people with learning disabilities leading their good lives and will, again, offer some hopeful examples where these challenges have been overcome.

Learning Disability England's aspiration is that this document will stimulate conversation and, more so, will galvanise action. We hope that, as with the first edition, you will consider this as an active invitation to engage with us to plan, act and deliver a more hopeful tomorrow.

Together, one pebble at a time, we can move mountains.

We look forward to working with you.

## Good Lives: Building Change Together

# ACKNOWLEDGEMENTS

We, at Learning Disability England, would like to express our continued gratitude to the many people with learning disabilities, their families, allies, and supporters who contributed their time, effort, and energy to inform the second edition of this report.

In these particularly difficult times, a special thank you goes to those who, despite adversity, continue to show that with resourcefulness, creativity, and a commitment to the rights of people with learning disabilities, we can find ways to navigate to a better place. And, by doing so they have lit a lamp for others to follow.

Thank you also to those who shared their personal stories and agreed for these to be used to illustrate what is possible when we look to gifts and strengths. Stories connect us to the heart of the matter. They are precious. This act of generosity often gets overlooked or taken for granted.

Thank you to Dr Sam Smith, founder and CEO of C-Change Scotland, for writing this second edition.

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# INTRODUCTION

“If we are to achieve a richer culture, rich in contrasting values, we must recognize the whole gamut of human potentialities, and so weave a less arbitrary social fabric, one in which each diverse human gift will find a fitting place” [Margaret Mead](#)


[Margaret Mead](#), cultural anthropologist and writer (1901-1978)

THE FIRST EDITION OF THE GOOD LIVES FRAMEWORK WAS ISSUED IN 2022. THIS WAS, IN PART, A RESPONSE TO THE FACT NO COMPREHENSIVE NATIONAL POLICY STATEMENT FOR LEARNING DISABILITIES HAD BEEN PUBLISHED IN ENGLAND SINCE THE VALUING PEOPLE – A NEW STRATEGY FOR LEARNING DISABILITY IN THE 21ST CENTURY IN 2009. IT ALSO REFLECTED A DESIRE TO UPDATE PUBLIC AND SERVICE ASPIRATIONS FOR PEOPLE WITH LEARNING DISABILITIES TO MAKE THEM FIT FOR THE 2020s.

This second edition of the framework builds on those original aspirations and provides an iterative update of the original document; a refresh rather than a comprehensive rewriting of the original. In the following themed chapters where positive developments have occurred, we have endeavoured to capture them. Where there has been regression, and we are aware of it, we aim to state the facts. Where there has been little or no change, we have noted that too.

The original document was intended to be viewed as a work in progress. This second edition should be considered in the same light. One area of progress is the inclusion of an additional chapter (Chapter 7) focussing on health for a good life. We know there are other areas that also need to be addressed.

We hope the framework will inform policymaking by providing a clear articulation of the needs and aspirations of people with learning disabilities, enabling policymakers to develop more informed and effective policies to address specific needs. In addition, by highlighting the importance of involving people with learning disabilities, their families and supporters in the policymaking process, we aim to ensure policy development will be more inclusive and representative of the diversity of voices. We also hope that the framework will serve as a useful tool for advocacy by raising awareness of the challenges faced by people with learning disabilities and the importance of addressing these issues. The framework reflects various evolving aspects of life such as housing, communication, relationships, advocacy, employment, and health and by doing so we hope to support a more holistic approach to policy formation.

 Look for the little dots in this document.  
Click them to get more information.

The framework also has the potential to be used as a benchmark for success by providing clear goals for what constitutes a ‘good life.’ It also offers guidance for how to navigate the required changes by signposting to others who have already made inroads and achieved some success. The hope is that the Good Life Framework guides policymakers in creating more effective, inclusive, and holistic policies that improve the lives of people with learning disabilities. It may also be seen as a starting point for a new national policy that we hope will emerge sometime soon.

In addition, we genuinely hope that this document can be used by individuals, families and community groups to support how they go about changing things for the better at a local level. We recognise that this is where most innovative change happens. There are great examples all over the country of individuals, families and services innovating, overcoming challenges, and creating solutions to ensure people live good lives. We do not need to reinvent the wheel or start from scratch. We believe that by sharing these examples we can inspire each other to continue to create more and better opportunities for people with learning disabilities, their families, and our communities.

The first edition of the Good Lives Framework informed the creation of the Good Lives Manifesto 2024. The Manifesto was written before the 2024 UK election to raise awareness and seek support from political candidates. It was the co-produced result of campaigns and actions that brought people and organisations together to agree the most important priorities for the then future government to progress to make good lives for people with learning disabilities possible.

This second edition of the Good Lives Framework incorporates the ‘Six big aims’ set out in the Good Lives Manifesto which are:

- 1 Be a champion for the rights of all people with learning disabilities, including people from minority ethnic communities and with high support needs.**
- 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.**
- 3 Have effective, reasonably adjusted health services that contribute to better health and raising life expectancy 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.**
- 5 Make sure people with learning disabilities have the same access to housing options as their non disabled peers.**
- 6 Make this an accessible general election.**

# THE LANDSCAPE

The first edition of the Good Life Framework was written in 2022, in the shadow of the Covid-19 pandemic which distorted the lives of individuals, families, communities locally and around the world. It also exposed existing inequalities and made them worse. Covid inquiries are currently underway to establish the real impact of decisions made during the crisis. What is clear is that some people were more affected than others. For example, according to the Race Equality Foundation, people with a learning disability were six times more likely to die from Covid and 40% of these deaths were people from Black and Pakistani communities. Some implications of the pandemic are only emerging as time passes.

Inequalities existed before the pandemic and have continued beyond the immediate impact. People with a learning disability die on average significantly younger than the general population and post-pandemic this trend continues. The latest reporting also shows that people from ethnic minority groups died at a younger age in comparison to people of white ethnicity. People with a learning disability are more likely to die from avoidable causes. They are also more likely to experience loneliness and social isolation and are significantly less likely to achieve educational qualifications. Only 4.8% of adults with a learning disability in England are in paid employment, compared to 75% of working age adults in the general population. They also experience a myriad of other social, health and economic disadvantages.

The ongoing human rights violations associated with children and adults with learning disabilities and/or autistic people living in assessment and treatment units remains despite cross-party agreement that this 'is a matter of national shame,' Rt Hon Jeremy Hunt MP, then the Chair of Health and Social Care Committee. A recent report challenged the persistent use of segregation and seclusion and identified the lack of therapeutic benefit associated with such practices.

## Intersectionality

Article 1 of the Universal Declaration of Human Rights (UDHR) says, "All human beings are born free and equal in dignity and rights," and that freedom from discrimination, as set out in Article 2 of the UDHR, is what ensures this equality. Being free from discrimination means that all discrimination must be prohibited, prevented, and eliminated.

In this respect people who are in the most vulnerable situations and who face the biggest barriers to realising their rights are prioritised. People whose rights are most at risk can vary from issue to issue. A non-exhaustive list (as others may be identified) of people whose rights may be most at risk includes: Black and minority ethnic people; care experienced people; children and young people; families of accused persons and people in custody; disabled people, including people with learning disabilities and autistic people; LGBTQIA+ people; lone parents; migrants, refugees and people seeking asylum; older people; people on remand; people in poverty; people with lived experience of homelessness; people with lived experience of substance use; people with long term conditions; people with mental health conditions; people with religious belief/faith; people living in rural or remote areas; Gypsy/Travellers; unpaid carers; and women.

All forms of discrimination should be looked at through an intersectional lens. 'Intersectionality' is used to describe the intersection of different and multiple characteristics that create interdependent and complex systems of power, discrimination, and disadvantage. Identity is complex; no one is just disabled. Disabled individuals also have an ethnicity, gender, sexuality, and economic background, as well as having other factors which impact on identity such as religion. These aspects of identity are lived simultaneously, and this is known as intersectionality.

Credit goes to the work of Professor Kimberlé Crenshaw, the First Minister's National Advisory Council on Women and Girls (NACWG) in Scotland, and others in the development of its definition.

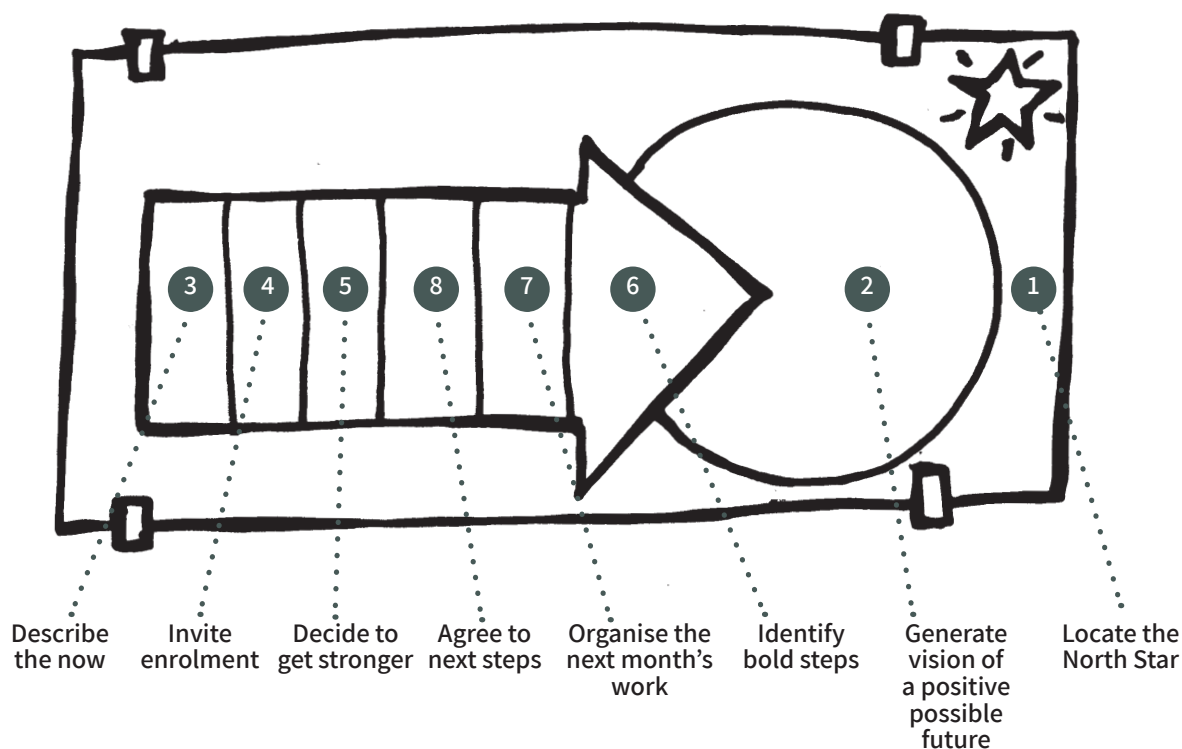


The Small Margins project heard this clearly:

“Disabled people always bring it back to disability and think you can understand racism because of the discrimination you have experienced as a disabled person, but it’s a whole different experience being disabled and also experiencing racism. In a way being disabled and experiencing racism can make it harder sometimes.”

## OUR PLAN

We wanted a structure to help to shape this work that felt inclusive and progressive. A process that symbolised a journey of improvement with both great expectations and realistic steps to help us move forward. We have chosen to draw on the person-centred planning PATH (Planning Alternative Tomorrows with Hope) process to guide this work.



We cannot determine the timescales as one generally would with an individual’s PATH, but we can set an aspirational direction of travel and ask others to enrol to make the ‘dream a reality’.

# OUR PREPARATION

As with the first edition the groundwork for this refreshed document started with asking learning disabled people and their families to set down what mattered most to them and what they felt needed to change in the future.

We maintained the principles set in 2020 of being led by what is most important to people and families – this version is a culmination of following those principles in action through the development of the Good Lives manifesto and the health chapter. People told us to keep a rights-based focus and solution approach.

We held online meetings throughout 2023 that were self-advocates only, families, supporters as well as joint sessions in person at the two LDE conferences and online. There have been surveys on the priorities as well as catch ups at member meetings. A small group of members acted as a sounding board and checking group on the manifesto development, and the Elected Members Representative Body have overseen the roll out and refresh. Find out more [here](#).

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## OUR NORTH STAR

A north star is not a destination,  
it is a direction of travel

What makes a good life is specific to each of us, and for all individuals the details are important. However, we know some general conditions are required for a good life to be possible. Disabled people were instrumental in drafting the UN Convention on the Rights of Persons with Disabilities (UNCRPD). It provides a human rights framework detailing those basic conditions. In this respect it outlines a floor, not a ceiling, for the necessary conditions for good life.

Eight guiding principles underpin the Convention and each one of its specific articles:

- 1 **Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons**
- 2 **Non-discrimination**
- 3 **Full and effective participation and inclusion in society**
- 4 **Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity**
- 5 **Equality of opportunity**
- 6 **Accessibility**
- 7 **Equality between men and women**
- 8 **Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities**

We will use this international human rights convention as the North Star to guide our work within this document.

Inclusion Europe made a short video that explains the UNCRPD that you can watch [here](#).

# OUR VISION

The challenges facing people with learning disabilities, their families and the communities and organisations that support them seem to have compounded since the first edition of the Good Lives Framework. It would be entirely understandable for people to feel a bit overwhelmed by the challenges that face them.

We want this document to be useful for local people, for it to inspire and to challenge, with the aim of changing things for the better. It deliberately focusses on solutions and possibilities. It highlights areas where gaps exist between intentions and actions and, by using examples, illustrates possible ways to bridge these gaps. We also hope that it may

be seen as a starting point for a new national policy that must emerge over the next few years.

We want to create, with others, the conditions for learning disabled people to flourish and to live their good life. To support this focus on a positive future we have intentionally adopted the principles of the Hope Based Communication approach.

- Shift 1 • Talk about solutions, not problems
- Shift 2 • Highlight what we stand for, not what we oppose
- Shift 3 • Create opportunities, drop threats
- Shift 4 • Emphasize support for heroes, not pity for victims
- Shift 5 • Show that “we got this”!

“Hope is the belief that destiny will not be written for us, but by us ... who have the courage to remake the world as it should be”

Barack Obama, 44th President of the United States of America

# THE ROUTE

This work is rooted in collaboration and is focussed on the explicit aim of improving the lives of people with learning disabilities and those who know and love them. Starting with what matters most we aim to build, with other willing allies, a better tomorrow and beyond. Fortunately, we do not need to start from scratch. There are many great examples of things that work well and ideas that can grow and be built upon. Building upon the great ideas detailed in the first edition of this framework is the explicit aim of this second edition. It is a continual work in progress of charting the incremental improvements, the inspirational ideas, the creative solutions that will step by step ensure that people with learning disabilities are able to take up their full role in society and lead their good lives.

The focus of original chapters in the first edition were drawn from the people we worked alongside or engaged with. We have built on these with our work with individuals and communities since then and this has informed the updates. Again, it is important to emphasise that the size of the chapter does not reflect the importance of the issue or theme. It is more a reflection of where our discussions and engagement have got to at the point of writing this second edition.

The chapter themes are also not exhaustive or inclusive of all the issues and challenges people with learning disabilities face. They represent those subjects raised by people we have engaged with and their families. We have added a chapter on health and wellbeing and have tried to address, at least in part, the subject of intersectionality. We know there is more to be done to represent the experience of the minority ethnic communities. We also recognise there are significant issues we have not addressed at all such as education, transport, poverty, and trauma.

This is not an oversight, more a reflection of the discussions and activities to date. We know we have more work to do.

This second edition of the Good Lives framework updates and builds on the first.

Our next attempt to articulate the constant process of change in all its untidy reality. Our world is not linear; it does not operate as a constant stream of progress. There is an ebb and flow. We want this document to be an honest reflection of world as the people we work alongside experience it.

We know that subsequent engagement, debates and deliberations will ensure that this document continues to evolve beyond this edition.

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# OUR TRAVEL COMPANIONS - ENROL

We embark upon this venture with humility. The work contained within this document is the collective effort of people with learning disabilities, their families and carers, activists, and professional allies. All credit goes to those who surmount challenges daily with courage and fortitude. All errors and mistakes are ours and we will rectify, adjust, and amend as necessary as this document develops.

Our destination is a more hopeful future and our collective action is the only way we believe we can get there. We hope that this document offers another step towards this end point.

All we ask of you is your willingness to get involved.

# CHAPTER 1: A HOME

“The ache for home lives in all of us, the safe place where we can go as we are and not be questioned”

Maya Angelou

Maya Angelou, Poet, storyteller, activist and autobiographer.

# WE ASKED AND YOU SAID

When we asked people what was important to them about home and family life, during the Big Housing Conversations and other events many of the responses echoed rights enshrined in the UNCRPD but are often yet to be realised. These are some of themes from the responses we received.

Many people said everyone should be able to choose where they live and who they live with.

This is our Human Right, the same as for people who do not have a learning disability.

A manager from a member organisation said, 'I want to see a change of language and culture, where we move away from "filling voids" to offering people an opportunity to live with others (if it is appropriate for them)'.

People said they think it is wrong that people with a learning disability are made to live in areas that are not safe.

People said the law needs to work better.

There was concern that more people will be made to live in care homes and hospitals because of a lack of money.

## HUMAN RIGHTS FRAMEWORK

The right to respect for private and family life is enshrined in Article 8 of the European Convention on Human Rights.

The UNCRPD provides a more detailed account of the rights of disabled people.

## ARTICLE 19 – LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The Equality and Human Rights Commission explain more about Article 19 in this easy read pdf [here](#).

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

# HUMAN RIGHTS FRAMEWORK

## WHY THIS IS IMPORTANT

There is a lack of good affordable housing in England that is impacting on many people.

People with learning disabilities are affected by the lack of social housing, affordable purchase options and quality too. Often people's choices are reduced further by their support needs or access to work opportunities.

The report, 'A lifeline for Lifetime Independence' was written by the Housing Learning and Improvement Network (LIN) and commissioned by the Learning Disability and Autism Housing Network and provides the most up to date information on the size, scope, cost, support and, importantly, future needs of supported housing in England for individuals with a learning disability and autistic people.

Through the analysis of existing evidence and by undertaking primary research, some key findings revealed that:

- 23% of this population live in mainstream housing with a care/support package, 15% live in residential/ nursing care settings, and 37% live with family and friends.
- between 35,000 to 37,500 people with a learning disability and autism currently live in supported housing.
- it is estimated that there will be shortfall of around 27,000 to 34,500 units of supported housing by 2037, or around 1,800 to 2,200 units per annum.

- Supported housing plays an increasingly critical role in enabling people with a learning disability and autistic people to live independently at the heart of their communities.
- at least 80% of supported housing for people with learning disabilities/autistic people in England is provided by Registered Providers of social housing.
- 83% of all supported housing for people with learning disabilities and autistic people is categorised in relation to housing benefit regulations as specified accommodation, either as exempt accommodation (44%) or managed properties (56%).
- The average weekly rent and service charge for supported housing for people with learning disabilities/autistic people is approximately £250 per week for self-contained housing and approximately £235 for shared housing.

The My Front Door research found that people with learning disabilities can successfully rent their own home and made several recommendations to landlords about how they can better support people as tenants. The research found that local learning disability strategies are lacking in information on rented housing for people. A national consultation identified a range of challenges in accessing rented housing for people wishing to do so. Interviews with people with learning disabilities renting their own place confirmed some of these problems but also, crucially, highlighted the success for most who rented their own home. People liked renting and were managing their tenancies well with relatively modest support.

Quilgars, D., Leishman, E., Abbott, D., Clarke, S., Cooper, B., Hodgkins, S., Scarrott, P., Pollin, A., & Beech, L. (2024). 'I wouldn't change my flat for anything'. Is there scope for more people with learning disabilities to rent their own homes? *British Journal of Learning Disabilities*, 52, 362–370.

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.

- We need to recognise the importance of the right home. This should be based on person-centred planning. The opportunity for people with learning disabilities, their families, housing providers, social workers etc. to come together and plan how to get the home they want and need. This would require 'needs-led housing development rather than build and fill'.

- There needs to be ongoing investment in information, resources and skills to support people to know and understand how to get access to housing that suits them.
- Government should create the conditions for growth of supply by allocating a higher proportion of the new affordable homes programme to new housing for people with learning disability and autism.

- In social housing there should be the adoption of a rent standard that supports the commissioning and funding of new supported housing for people with high support needs.
- Coordinate housing delivery across housing, health, and care, aligning with new strategic planning duties of the Supported Housing (Regulatory Oversight Act) 2023.

- There needs to be a quicker and less bureaucratic way of accessing grant funding from NHS England to develop housing for people who need to leave an assessment and treatment unit.
- It should be possible for people to have a home close to their families and other supporters; this helps to build on local connections and 'natural' support.

- A long-term sustainable, consistent housing benefit regime for supported housing should be created.
- Integrate people with learning disabilities into the Government's Housing Strategy: Making access to social housing or supported housing a key component of the government's long-term housing plan.

- We need to develop a consistent approach to support people with learning disabilities to hold a tenancy without recourse to a (Court of Protection) appointed deputy; this approach should be promoted to general housing providers.

- A recognised 'national standard' should be created detailing what housing rights and options people with learning disabilities are entitled to. Local councils should have to meet this standard.
- Advocacy support should be routinely available for people who don't have family to support them to exercise their housing rights.

- There should be recognition and acceptance amongst professionals and housing providers that people with learning disabilities may want to move home at different times during their life; just like other people choose to do.

- Funding should be available which supports people to live good lives, fosters independence and enables contribution. This should be in addition to money that pays for personal care (for people who need that as well as support).

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

## Good example 1

Paradigm have produced the Reach Standards which they describe as ‘a guide dedicated to people who want to raise expectations, continually question and improve the world around us’.

Reach Standard 1 • I choose who I live with.

Reach Standard 2 • I choose where I live.

Reach Standard 3 • I have my own home (with a tenancy or ownership).

“I think it’s also important that we get more people with learning disabilities out of long stay hospitals, ATU’s and Residential homes where possible and back into the community in housing that is suitable. The money needs to be available to do this”

Gary Bourlet, Membership and Engagement Lead, LDE

## Good example 2

LDE have produced a housing guide to support independent living for everyone. It explains the concept of independent living, different housing options and how to get and maintain your own home.

“Our goal is to see people with learning disabilities in the mainstream of life, living in ordinary houses and ordinary streets, with the same range of choices as any citizen, and mixing as equals with the other members... of their own community”

David Towell

David Towell 'An Ordinary Life in Practice: Developing Comprehensive Community based Services for People with Learning Disabilities'  
London: The King's Fund, (1988).

### Good example 3

Disabled Facilities Grant funding allocation to Councils has been increased. The grant can help people stay in their home or make a home accessible to them. This includes children and their families.

### Good example 4

The Challenging Behaviour Strategy Group have coproduced an action plan to end the misuse of specialist mental health hospitals. This includes actions on the right housing to stop people going into hospital and for those who are prevented from leaving.

NHS England working with the Housing Association Charitable Trust has produced resources to support mental health hospital to home discharge planning for autistic people and people with a learning disability.

# WHO DO WE NEED TO ENROL/ENGAGE?

There is a range of ideas we can work on together. Some, such as changes to the benefits system require systems change at a government level. Strong advocacy will be required to push this agenda.

Others, such as recognising and prioritising the right to a home and family life can be built on relatively quickly through sustained citizen action. Focused attention needs to be given to strengthening alliances with housing, advocacy, carers and human rights organisations. Actively raising aspirations based on respecting, protecting and fulfilling human rights provides a unifying framework for this work.

## NEXT STEPS/FIRST STEP

There seems so much to do that it would be easy to get despondent, however that does not make things any easier for learning disabled people and their families.

When things are difficult, more than ever, we need to be inspired by the power of the possible. Our first step should be to build on the good examples we have detailed above.

### FOR SERVICE PROVIDERS

We need to recognise the importance of the right home. This should be based on person-centred planning. The opportunity for people with learning disabilities, their families, housing providers, social workers etc. to come together and plan how to get the home they want and need. This would require 'needs led housing development rather than build and fill.'

People's rights and security of tenure should be enshrined in all planning and delivery of housing for people with learning disabilities guided by the Real Tenancy test.

### FOR GOVERNMENT

**The Good Lives Manifesto** proposes that the government should recognise that failing to produce a national policy supporting people with learning disabilities since 2009 has seriously limited the ability of people and their families to influence and be part of policy formation. This has directly impacted the quality of policy development and consequently, the lives of people with learning disabilities.

**The ask:** Put 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.

### The Good Lives

**Manifesto** asks the government to recognise that people with learning disabilities experiences and life chances are significantly different to other peoples. They are more likely to live in poor housing environments, be in poverty and be bullied or discriminated against.

**The ask:** Action is needed to remedy the systemic disadvantages experienced by people with learning disabilities. Premature mortality needs to be addressed by focussing on the social determinants of health. This will require cross government action.

**The Good Lives Manifesto** calls to end the use of secure hospitals as homes for people with learning disabilities. 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.

**The ask:** The government needs to meet its human right obligations by appropriately funding rights compliant support in the community aligned to the Social Care Futures description of a brighter future.

‘We all want to live in the place we call home, with the people and things we love, in communities where we look out for each other, doing the things that matter to us.’

**The Good Lives Manifesto** highlights the need for the government to take direct action to level up social housing so people with learning disabilities, alongside others have access to safe and secure accommodation.

**The ask:** The government must support national and local annual targets to build supported housing for people with learning disabilities and publish the number and type of accommodation funded.

## FOR LOCAL AUTHORITY COMMISSIONERS

Local Councils should make sure all housing options meet a set of core standards for the options, and quality available to people alongside rights including the Real Tenancy Test.

Funding should be available which supports people to live good lives, fosters independence and enables contribution. This should be in addition to money that pays for personal care (for people who need that as well as support).

## FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

There needs to be investment in information, resources and skills to support people to know and understand how to get access to housing that suits them.

# CHAPTER 2: COMMUNICATION AND STAYING CONNECTED

“The most basic of all human needs is the need to understand and be understood. The best way to understand people is to listen to them”

Ralph G. Nichols

Ralph G Nichols, author of Are You Listening.

# WE ASKED AND YOU SAID

People with learning disabilities and/or autistic people often face barriers to being included in both the real and the digital world. When we asked people what was important to them about communication and connection, these were some of the responses we received.

People with learning disabilities, their families and supporters want relevant information that makes sense to them at the same time as everyone else.

People often don't know or understand their rights on inclusive communication support including things like Speech and Language Therapy (SALT).

Ensuring access to digital communication has made a huge difference for lots of people who can now be in touch with others or work remotely.

Some people's communication needs are not supported or invested in consistently across services and areas.

There are a lot of opportunities to learn from others, locally, nationally and internationally.

Accessible information is necessary for people to keep themselves healthy, safe and well.



## HUMAN RIGHTS FRAMEWORK

The right freedom of expression is enshrined in Article 10 of the European Convention on Human Rights.

The UN Convention on the Rights of Persons with a Disability (UNCRPD) provides a more detailed account of the rights of disabled people.

## ARTICLE 21 – FREEDOM OF EXPRESSION AND OPINION, AND ACCESS TO INFORMATION

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

- a Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
- b Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions.
- c Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
- d Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
- e Recognizing and promoting the use of sign languages.

British Institute of Human Rights made an easy read guide with self-advocates to rights to accessible information.

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

HUMAN  
RIGHTS  
FRAMEWORK

## WHY THIS IS IMPORTANT

Research shows that in relation to people with a learning disability in the UK, 88% of families and carers surveyed said their loved one was always or very often felt sad, and 82% felt lonely due to rarely being able to leave their homes. Nearly a third (32%) were struggling with mental health issues, including suffering from low mood and low self-esteem.

People with learning disabilities often find it difficult to communicate their feelings and struggle to get the help they need, “although people with learning disabilities may not be socially isolated, even with people around them they can often still feel lonely.”

1 in 3 young people with learning disabilities spend less than one hour outside their home on a typical Saturday.

People with learning disabilities often face barriers in accessing digital devices and the internet. This can be due to financial constraints, lack of appropriate devices, or sufficient internet connectivity.

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

# HUMAN RIGHTS FRAMEWORK

# IDEAS WE CAN WORK ON TOGETHER

We have gathered ideas for 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 shown here.

Ensuring readily available accessible information so that disabled people have the same opportunities and can make informed choices based upon good information. This would require:

- A government-wide communications plan for making sure information is available quickly, meets accessible standards, is coproduced with people from diverse groups and is easy to find in one place.

- Respect of the various ways people with learning disabilities might communicate and investment in supporting different approaches like Intensive Interaction, Makaton, picture systems and more.

- Dissemination that is supported by a national coproduction group with resources available for local learning disability, autism and family carers organisations to use and share.

- Production of accessible information to be understood as an essential part of mainstream government communications strategies, not a separate or add-on task.

- The development of a longer-term strategy for developing accessibility with large institutions such as the BBC.

- People with learning disabilities and their families knowing their rights to accessible information and communication support or adaption – (provided as part of any Care Act related contact).

- Concerted effort to promote and develop accessible technology that respects diversity and works for people.

- Belief that people with learning disabilities have the right to access both technology, and support to enable them to access that technology.

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

## Good example 1

United Response has supported the creation of Easy News ‘the first news magazine designed to be accessible for people with learning disabilities, aimed to encourage discussion around news stories and keep readers informed about the world around them.’ This is available to anyone. All you need to do is sign up and you will receive the latest edition of Easy News in your inbox.

“I have enjoyed being able to connect with different groups across the country. We were also able to connect with self-advocates in Ghana, which the group found interesting as they were able to learn about how they do things”

Kim from KeyRing

## Good example 2

The accessible information campaign group worked with BIHR to produce an accessible and easy to use resource on information and rights. They also created an Easy Read Guide to the Human Rights Act.

## Good example 3

The Digital Lifeline Project helped 5,500 people with learning disabilities get online by distributing a device, data and assistive technology. 52% of the people reported afterwards they felt less lonely because of the device.

This built on the work of self-advocacy groups and support organisations through the pandemic to support digital inclusion.

## Good example 4

The Valuing People Alliance has coproduced some top tips of how health and social care services, partners and others should work to ensure that people with learning disabilities and autistic people can be digitally included.

### Good example 5

Communication Top Tips for healthcare staff resources were developed by the Northeast and Cumbria Learning Disability Network and were coproduced with the Involving Everyone group. The resources are designed to give all healthcare professionals some tips and phrases to support them when meeting and communicating with people with profound and multiple learning disability, no matter how brief their involvement may be.

### Good example 6

Many self-advocacy groups are working with local partners to develop and share accessible information. For example: ESCC & the Involvement Matters Team develop easy read information and have just developed easy read web pages. Involvement Matters Team have an easy read reference group where self-advocates review information and put their stamp of approval before it can be agreed and sent out. They have supported the development of an Easy read Total Communication pack. The group has helped trial the NHS App and is co-delivering Digital Lives training.

# WHO DO WE NEED TO ENROL/ENGAGE?

There are some actions, such as recognising accessible information as an essential component of mainstream communication strategies, that needs to happen at a government level. This is unlikely to happen without strong cross sectoral campaigning led by people and their families and supported by allies.

Commissioners, providers and advocacy organisations can increase awareness of the need for accessible information. They can also commit to improving the accessibility of the information they disseminate.

Individuals, self-advocacy groups and families can keep the pressure up by knowing and understanding their rights to accessible information and requesting these rights are respected, protected and upheld.

## NEXT STEPS/FIRST STEP

### FOR SERVICE PROVIDERS

Establishing collaborative partnerships between those who provide in-house support (e.g. care homes, supported living; family members) and those who have the experience and expertise to provide remote support (e.g. self-advocacy groups, day services).

Collect, curate and share innovative examples of how technology was used by people with learning disabilities during the pandemic to help others understand the evolving potential of technology to enhance lives.

Implement the Accessible Information Standard in health and social care service provision.

### FOR GOVERNMENT

**The Good Lives Manifesto** highlights the need for the government to make concerted efforts to address the barriers experienced by people with learning disabilities in relation to digital inclusion.

**The ask:** The Government should ensure that people with learning disabilities are included in digital inclusion projects including access to equipment, Wi-Fi and levelling up equipment schemes.

### FOR COMMISSIONERS

Education, health and social care commissioners and providers need to understand the 'digital divide' faced by people with learning disabilities and develop a clear plan to address

- **Access to technology (the kit).**
- **Access to support to know and understand how to use technology.**
- **Ensuring affordability of technology – internet access, data charges etc.**

Commissioners should include digital inclusion, facilitation and support skills and access to Wi-Fi or data in service specifications.

Commissioners should understand the existing local resources that support communication for people with the most complex needs and ensure there is access to Speech and Language specialist support as well as a range of communication tools and skills to enable people to use them.

## **FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES**

A cultural shift is required that supports the idea of access to communication and connection as a human right. This should be supported by capacity building programmes for both people with learning disabilities and their supporters (including family members) so that they can confidently use technology as well as specialist communication systems when needed.



# CHAPTER 3: THE RIGHT SUPPORT

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has” Margaret Mead

Margaret Mead (December 16, 1901 – November 15, 1978) was an American cultural anthropologist who featured frequently as an author and speaker in the mass media during the 1960s and 1970s.

# WE ASKED AND YOU SAID

We held a series of conversations and activities exploring the importance of the right support, this included meetings about the Social Care white paper as well as work by members. We have also engaged with a range of other organisations committed to improving social care. Some consistent themes emerged from this work, many of which are reflected in human rights conventions, most notably the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

These are some of the key issues that learning disabled people and their families raised with us.

Embed and revive person centred thinking and planning tools - around good support, matching the right people together and empowering people to raise concerns effectively without reprisal (family member).

Reinforce the idea that social care is about life, not services.

Consistency in people and relationships really matter to everyone.

Relationships should be based on trust and equal power.

People feel forgotten when policy development appears focused on support for older people.

Investment means both money and a willingness to change, not just the former.

## HUMAN RIGHTS FRAMEWORK

The right to a private and family life is enshrined in Article 8 of the European Convention on Human Rights.

Article 14 of the Convention further prohibits discrimination. It secures the enjoyment of the rights and freedoms in the Convention, without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

The UNCRPD provides a more detailed account of the rights of disabled people, particularly in relation to access to appropriate support.

## ARTICLE 26 – HABILITATION AND REHABILITATION

- 1 States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
  - a Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
  - b Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
- 2 States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
- 3 States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

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

# HUMAN RIGHTS FRAMEWORK

## 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 prioritised in policy. In March 2023, 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. It has identified 5 key actions towards this vision and coproduced evidence of how to make these key changes.

Social care is facing significant financial pressures. In the 2023 Sector Pulse survey 40% of providers reported operating with a

financial deficit. Of those surveyed 85% of providers reported that government funding initiatives implemented across 2022 had no impact upon their financial sustainability.

As a result, 18% of providers offered care and support to fewer people, while 39% of providers considered taking steps to close altogether.

One of the most significant cost pressures is annual increases in the National Living Wage. 79% of providers reported that local authority fee increases did not cover the full cost of National Living Wage increases in 2023. Support workers' pay should reflect their skill and value with the living wage being the very least that should be paid the issue to be addressed is appropriate levels of funding that ensure social care providers can operate on a whole cost recovery basis.

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. 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.

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 areas they, and their families, said are important to them.

People spoke strongly about the importance of developing trusting consistent relationships. This may be achieved through the following steps:

- Service providers effectiveness could be measured on how they recruit, support and retain consistent employees.
- Provider effectiveness could be measured on the steps they take to ensure the support they deliver is person led. That any support provided adapts and evolves as the person's lifestyle and preferences develop and change.

- Ensuring the pay and conditions for the social care workforce reflects their value as 'key workers', including reasonable payment for all hours worked, including sleepover hours.

- The Association of Directors of Social Services (ADASS), Local Government Association (LGA) and NHS England (NHSE) place greater priority on relationship focussed recruitment and retention practices. Including requiring that commissioners co-design practice guidance with local people who draw on support.

- Invest properly in all support services so the funding given covers the real cost of delivering quality, person led support and helps create consistent support structures where people supported and those supporting can flourish.

- Reorienting service structures to deliver for people who draw on support. This would require commissioners and providers to work in service to people, if necessary, fundamentally redesigning what they deliver. Shifting to what people want, not what is currently exists.

- Re balancing power arrangements to ensure the will and preferences of the supported person is the priority. Changing the measure of success to be whether it works for the person.

- Implement and measure against the REACH standards.
- Quality standards and regulation led by people who draw on support and their families and based on what matters most to them.

- Make sure the Employment Rights Bill includes improvement to direct support worker pay and wider terms and conditions properly funded through social care rates of funding

- Implement the workforce strategy ensuring all the workforce supporting people with a learning disability are enhanced and non-regulated services are not restricted by the plans.

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

## Good example 1

Paradigm has developed REACH Standards that detail what good looks like. Commissioner and Providers should be using this as a framework to develop local service provision alongside local people and families who draw on support.

“ Support staff matters because without them we might not achieve what we achieve and people might miss out on things life ”

Mary Woodhall, Member Representative

## Good example 2

Flourishing Lives shares tools, resources and evidence to help supporters and organisations focus on assisting people build their good life. They include examples of how this is happening as ‘Drops of Brilliance’.

## Good example 3

Changing Our Lives has been working to highlight the fact that across disability movements and society in general, the lives and experiences of disabled people from minority ethnic communities are often overlooked and obscured from view. Oral histories of disabled people rarely mention the lives of individuals from minority ethnic communities; likewise, oral histories from minority ethnic communities rarely mention the lives of minority ethnic disabled people. Changing Our Lives is committed to preserving these invisible histories, on both an individual and collective level. Colour Between the Lines emerged from this belief.

## Good example 4

Building alliances with community groups, advocacy and campaigning organisations on issues of common cause can amplify the call for positive change. LDE actively contributed to the campaigning work of Social Care Futures. Ensuring the voice and views of learning-disabled people contribute to calls for more responsive, person led social care support.

The Social Care Future report calls for five key changes ‘To unlock an equal life’. Here are the changes being called for:

- Communities where everyone belongs.
- Living in the place we call home.
- Leading the lives we want to live.
- More resources, better used.
- Sharing power as equals.



## Good example 5

The Small Margins project worked with people with a learning disability, autistic people and their families from minority ethnic communities (South Asian, African Caribbean, Black African and dual heritage) who either lived in their own home (supported living), lived in residential care, or were moving out of inpatient hospital settings. It also included people who lived within the family home as data suggests that proportionally less people from minority ethnic communities live in residential care or supported living when compared with white people.

The Small Margins project sought to identify:

- The Small Margins Project shares people's experiences and can inform future learning.
- Future learning.

## Good example 6

The Why are we Stuck in Hospital project led by Researchers from Birmingham University undertook research seeking to better understand the experiences of people with learning disabilities and/or autistic people in long-stay hospital settings, their families and front-line staff. This knowledge was then used to create practice guides and training materials to support new understandings and ways of working.

## Good example 7

The Sensory Projects produced a set of Core and Essential Service Standards for Supporting People with Profound and Multiple Learning Disabilities. The document was developed by over a hundred people (including parents, family carers and professionals from all walks of life) who all have a particular insight into the lives of people with profound and multiple learning disabilities.

Glasby, Jon, et al. "Why are we stuck in hospital? 'Barriers to people with learning disabilities/autistic people leaving' long-stay hospital: a mixed methods study." *Health Services and Delivery Research* 12.3 (2024): 1-119

# WHO DO WE NEED TO ENROL/ENGAGE?

There are some areas of activity where high-level government support is needed, such as ensuring pay and conditions for the social care workforce reflects their value as ‘key workers’. This includes reasonable payment for all hours worked, including sleepover hours. However, this is unlikely to happen without strong campaigning led by unions, anti-poverty organisations, provider organisations and by people who access support, their families, and allies.

Individuals, families, advocacy organisations and allied campaigning organisations can increase the demand for relational, rather than transactional based support. Demanding that measures of effectiveness are rooted in the persons experience and framed by the REACH standards.

Individuals, self-advocacy groups and families can sustain the pressure to improve by knowing and understanding their human rights, in relation to accessing support and requiring these rights are respected, protected and upheld.

## NEXT STEPS/FIRST STEP

### FOR SERVICE PROVIDERS

There needs to be a cultural and practical shift by Commissioners and Providers from the purchase and provision of support determined by ‘industrial measures’ of time and task. Instead, they need to move to relational measures of impact, defined by the person. Success being measured by whether it is delivering what people are looking for.

### FOR GOVERNMENT

**The Good Lives Manifesto** clearly states the position of people with learning disabilities and the need for appropriate social care support for the government to meet its human rights obligations and ensure people can live good lives.

**The ask:** Support the Social Care Future movement vision and a set of strategic actions where funding is seen as an investment in people’s lives on the basis that, ‘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.’

**The Good Lives Manifesto** outlines clearly the need to recognise the breadth and depth of

social care support and the importance of ensuring that those who rely on it also inform its design and it is organised and delivered.

**The ask:** Make sure people drawing on social care and their families are included in social care policy, design and delivery to ensure it focuses on person-centred and culturally competent approaches.

### FOR COMMISSIONERS

Education, health and social care commissioners and providers need to redefine how they measure what good support looks like and base it on what matters to people who draw on support and their families.

The Paradigm REACH standards should be adopted as guide for delivering good social care support.

## FOR ALL LOCAL COMMISSIONERS

Education, health and social care commissioners and providers need to redefine how they measure what good support looks like and base it on what matters to people who draw on support and their families.

## FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

Concerted efforts should be made to create active alliances across sectors to promote areas of common concern such as the fair payment for social care workers for all hours worked, including sleepovers.

# CHAPTER 4: TO LOVE AND BE LOVED

“You’ve got to have something to eat and a little love in your life before you can hold still for any damn body’s sermon on how to behave”

Billie Holiday

Billy Holiday (1915 – 1959), known professionally as Billie Holiday, was an American jazz and swing music singer. Nicknamed “Lady Day”

# WE ASKED AND YOU SAID

People with learning disabilities and/or autistic people often face barriers establishing and maintaining relationships. We asked people what was important to them about relationships and the opportunity to love and be loved and these are some of the responses.

Adult loving and sexual relationships are not prioritised and supported. Support services place barriers in the way of people living full social lives.

Family relationships are often not prioritised particularly for people living in congregate settings.

Family relationships are often seen through the prism of support rather than loving family relations.

There is a concern that services will not value people's relationships long term.

Withdrawal of support leaves families struggling; unpaid 'carers are financially underpaid and emotionally under supported'.

Concerns about the quality of support available puts pressure on families worrying what will happen when they are no longer able to support their loved ones.

Adult sexual relations are seen as a health issue rather than a right.

## HUMAN RIGHTS FRAMEWORK

The right to respect for private and family life is enshrined in ARTICLE 8 of the European Convention on Human Rights. It states that:

- 1 Everyone has the right to respect for his private and family life, his home and his correspondence.
- 2 There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.●

The UN Convention on the Rights of Disabled Persons provides a more detailed account of the rights of disabled people, particularly in relation to personal and intimate relations.

## ARTICLE 23: RESPECT FOR HOME AND THE FAMILY

- 1 States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that: (a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized; (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided; (c) Persons with disabilities, including children, retain their fertility on an equal basis with others.
- 2 States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

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

# HUMAN RIGHTS FRAMEWORK

- 3 States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.
- 4 States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.
- 5 States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

### WHY THIS IS IMPORTANT

The evidence from the Reigniting debate and stimulating momentum for change project suggests people do not have the same opportunities to live an ordinary life as non-disabled people do. This includes having partners, friends and an active life of their choosing.

Research highlights that people with learning disabilities often face significant barriers but despite that still placed a high value on romantic relationships. A lack of social opportunities can make it difficult for people with learning disabilities to find love. Barriers are sometimes created by social care services. However, specialised dating agencies, along with strong family and staff support, may help people to form relationships.

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, and their families, said are important to them.

People spoke strongly about the importance of respect and support for healthy family relationships. Also, the desire for opportunities to love and be loved, in the widest and most inclusive sense. These ambitions may be achieved through the following steps:

- We should ensure that the right to family life is embedded in service standards and commissioning. Formal support services would be required to make explicit reference, and adhere to, the supported persons will and preferences with regards to family relationships.

- Adopting an explicit Human Rights based approach to frame service design and practice development. Ensuring that staff support LGBT+ people with a learning disability with their relationships and/or gender identity.

- Updating and upgrading the use of person-centred planning tools and plans - around relationships and Circles of Support. Examples and training nationally and locally.

- Recognition that people with learning disabilities may require additional support to exercise their will and preferences in relation to sex, sexuality and relationships. Ensuring this support is available.

- Ensuring that people with learning disabilities and/or autism are aware of their sexual rights.
- Sexuality and relationships should become a mandatory focus in Care Quality Commission (CQC) inspections, in the Key Lines of Enquiry.

- All social care workers undertaking training on supporting sexuality and relationships, using a rights framework.

- Support providers adopting the No Bedtimes guide, ensuring people can develop and maintain friendships and relationships by attending events and activities evening, weekends and as late as the person desires.

- Adoption of the Stay up Late manifesto pledges by commissioners and support provider.

- Social workers and commissioners using rights-based standards, such as REACH, to measure progress towards explicitly rights-based practice.

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

## Good example 1

Supported Loving is a human rights-based campaign, with associated network meetings, hosted by Choice Support. The campaign actively promotes the belief that people with learning disabilities and/or autism should be able to enjoy the same sexual and romantic freedoms as everyone else. The campaign highlights the fact that 3% of people with learning disabilities live as part of a couple compared to 70% of the general population.

“For people with learning disabilities finding love is often more than just chemistry - it can come down to getting the right support from your staff”

## Good example 2

Stay up Late is a registered charity committed to promoting the rights of people with learning disabilities to live the lifestyle of their choosing. It is particularly concerned that people with learning disabilities, and autism, aren't able to Stay Up Late and do the things so many people, who don't need support, take for granted.

The charity recognised that people with learning disabilities often aren't able to lead full and active social lives because their support workers finish at 10pm. This means lots of people with learning disabilities leave events at 9pm.

Recognising that people with learning disabilities have the same right to stay up late and have fun as anyone else Stay up Late have campaigned to raise awareness of the issue, issuing a No Bedtimes guide and a Manifesto for an Ordinary Life.

## Good example 3

United Pride Friends are a User Led group for LGBTQ+ people with autism and learning difficulties. It offers a safe space that is accessible, accepting and confidential. The group organise social events as well as promoting peer support and wellbeing.

# WHO DO WE NEED TO ENROL/ENGAGE?

There are many actions that flow from the ‘we asked you said’ and the ‘ideas that we can work on together’ that do not require high level government action. Citizen action and co-ordination can bring about many of the desired changes that will have a significant positive impact on the lives of people with learning disabilities and their families. One only need look at the Stay Up Late campaign to see what impact a small, committed group of people can have.

Building alliances of individuals, advocacy and campaigning groups, funders and human rights organisations around the issue of the right to love and be loved could have far reaching consequences. It will need a concerted commitment to dismantle the discriminatory service system barriers that inhibit opportunities for people with learning disabilities. Commissioners and regulators can play their part by requiring evidence of active support with this aspect of everyday life as standard.

## NEXT STEPS/FIRST STEP

### FOR SERVICE PROVIDERS

Support providers adopt the No Bedtimes guide.

Develop alliances of interested parties to promote the right to love and be loved, building on the good work undertaken to date.

### FOR GOVERNMENT

#### The Good Lives

**Manifesto** clearly states the position of people with learning disabilities and the need for appropriate social care support for the government to meet its human rights obligations and ensure people can live good lives.

**The ask:** Support strategic actions where funding is seen as an investment in people’s lives on the basis that, ‘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.’

Care Quality Commission (CQC) prioritise sexuality and relationships during inspections.

### FOR COMMISSIONERS

Education, health and social care commissioners and providers need understand the right to a private and family life and ensure that this is incorporated into service standards and practice.

All social care workers undertake training on supporting sexuality and relationships, using a rights framework.

REACH standards should be adopted as basic standards for supporting good lives.

### FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

A co-ordinated campaign to raise awareness of sexual rights among people with learning disabilities and or autism, families, and professionals.

# CHAPTER 5: EFFECTIVE VOICE - SELF ADVOCACY/ADVOCACY

“When the world is silent, even  
one voice becomes powerful”

Malala Yousafzai

Malala Yousafzai is a Pakistani advocate and activist for female education and the youngest Nobel Prize laureate.

# WE ASKED AND YOU SAID

People with learning disabilities and/or autistic people often face barriers making or informing key decisions in their own lives. When we asked people what a good life would look like and what was important to achieve this, self-advocacy and access to independent advocacy was a recurring priority. Some of the responses we received were;

Experience is more important than qualifications.

Let people take risks.

We need to raise awareness of our rights, using the law.

We need easy read, accessible information.

Be inclusive: if it is about people with a learning disability it should be led by people with learning disabilities.

People with learning disabilities should be paid for the work they do and the knowledge they bring.

Use respectful language (no service user).

Include people with profound disabilities.

We may have different ideas than our families.

**“Be my microphone not my voice”**

Dave Hingsburger, campaigner, writer, powerful advocate and public speaker.

## HUMAN RIGHTS FRAMEWORK

The right to freedom of expression is enshrined in Article 10 of the European Convention on Human Rights.

The UNCRPD provides a more detailed account of the rights of disabled people in Articles 5 and 17.

### ARTICLE 5 – EQUALITY AND NON-DISCRIMINATION

- 1 States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
- 2 States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
- 3 In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
- 4 Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

## ARTICLE 17 – PROTECTING THE INTEGRITY OF THE PERSON

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

### WHY THIS IS IMPORTANT

‘Independent advocacy is an essential component of the health and social care system, offering support to people who are at risk of exclusion. Access to independent advocacy helps people say what they want, secure their rights, represent their interests, and obtain services they need – in relation to the health, social care, education systems and beyond. This is particularly important to people with a learning disability and autistic people who experience many barriers to inclusion and in accessing community services which can result in being detained in mental health inpatient settings where they experience a number of restrictions.’

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:

- Inclusion in decision making – revive ‘nothing about us without us’ ensuring peoples views inform decisions that affect them. Make sure this includes Black Asian Minority Ethnic people as well as those with higher support needs. All means all.
- Ensure readily available accessible information so people have the same opportunities and can make informed choices based upon good information.
- Create a national network to work alongside national decision makers. Co-ordinating and amplifying local advocacy work ensuring maximum impact on national policy and practice.
- Collate evidence on the impact of self / peer advocacy. Make this publicly available.
- Highlight the need for investment in training / skills for leadership roles and for learning disabled self-advocates at the same level as non-disabled employees in health and social care.
- Investment in advocacy and self-advocacy by all local and national agencies where decisions are made that impact on people with learning disabilities.
- Support people from Black Asian and minoritised ethnic communities to develop self-advocacy and ensure existing structures create space for minoritised community voices.
- Implement models like Making it Real markers to ensure contribution to quality and accountability in local services. ●
- Increase human rights awareness through increased collaboration with Human Rights based organisations such as the British Institute of Human Rights. ●



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

## Good example 1

Together with My Life, My Choice and British Institute of Human Rights produced an accessible resource for people with learning disabilities who have been placed in long stay hospitals either unnecessarily or for too long. It aims to inform them about their human rights and how to use these effectively to challenge their stay.

## Good example 2

Filling in the Gaps report describes research by The Open University on the role of self-advocacy groups in supporting the health and wellbeing of adults with learning disabilities during the coronavirus pandemic. The research showed how and where self-advocacy was ‘filling in the gaps’ left by other services.

Funding The Gap report describes research undertaken by The Open University about how self-advocacy groups for people with learning disabilities are funded. This is important because lots of groups have closed because they do not have money, and others are struggling to survive.

The researchers wanted to know how and why local authorities and Clinical Commissioning Groups fund self-advocacy in some areas, but not others. How groups are funded when they receive little or no funding from local authorities. The pros and cons of different types of funding from the perspectives of self-advocacy groups. They came up with a series of recommendations for how to strengthen self-advocacy.

### Good example 3

The Making Sense of Self Advocacy Today report detailed the state of self-advocacy for people with learning disabilities in England in 2018-19 and provided suggestions for how to strengthen it. One example was Ace Anglia's work with its local authority and clinical commissioning groups which highlighted the benefits of partnership working. This arrangement provided both a route to funding and local influence, including co-producing the Learning Disability Strategy and securing funding to support peer education in relation to Annual Health Checks. They also successfully campaigned for Stowmarket rail station to become step free.

“It sort of makes sense to talk about ‘earning money’ rather than ‘getting funding’”

Self-advocate

## Good example 4

In 2022, The Henry Smith Charity launched a £2.6 million Strategic Grant programme to support 15 organisations providing advocacy services for individuals with learning disabilities and autism across the UK.

This three-year programme was designed to support high-quality advocacy services and foster evidence-based practice. To evaluate the programme, The Henry Smith Charity has teamed up with Social Finance as their learning and evaluation partner, and Speakup, a user-led organisation championing the voices of those with lived experience of autism and learning disabilities. The final report shows the benefits of nonstatutory advocacy including generating benefits of £12 for every £1 spent and increased wellbeing.

### Good example 5

The Equal Treatment project was completed over 2022. The project worked with 3 partners and aimed to challenge racism and health inequalities through strengthening self-advocacy and peer support. The project helped groups think about how to be more inclusive and helpful allies to tackle racism.

### Good example 6

In 2022, Learning Disability England heard from some people that there is not a lot of leadership or speaking-up training that includes minority ethnic people with learning disabilities and autistic people. LDE was advised that training about different people's experiences and anti-racist practice was not accessible to many autistic people and people with learning disabilities. LDE learnt about this by working with people and organisations as part of the Equal Treatment and Working Together to get the job done projects. The outcome of this work was a report called Learning to Lead.

### Good example 7

The NDTi, alongside Bringing us Together, the Challenging Behaviour Foundation, People First Independent Advocacy and Speakup Self Advocacy undertook a review to find out what was getting in the way of people receiving effective and timely independent advocacy as well as identifying factors which enable advocacy to work well. The review produced a report available in easy read, a summary, and a full version.●

### Good example 8

AccessAva is an online AI-driven service that makes expert legal support available 24/7 ‘ensuring that everyone can navigate the complexities of accessing health and social care with ease and confidence.’●

# WHO DO WE NEED TO ENROL/ENGAGE?

As can be seen by the range of ideas we can work on together some may require funding and co-ordination at a government level. Strong advocacy will be required to push this agenda.

Others, such as increasing human rights awareness can be progressed relatively quickly through concerted citizen action. Also, by strengthening alliances with skilled and knowledgeable human rights organisations.

Good practice examples can be used to recruit local authorities and clinical commissioning groups receptive to the positive potential of partnership working.

## NEXT STEPS/FIRST STEP

There are several initial steps that can be taken by just agreeing this is the way we want things to be and standing up and asking.

### FOR SERVICE PROVIDERS

Increase the opportunities for self-advocacy organisations to learn and share to grow capacity.

### FOR GOVERNMENT The Good Lives

**Manifesto** requires that 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.

**The ask:** that the government supports the development of self-advocacy national networks through the disability strategy. And that it ensures that self-advocates or user led organisations are a part of all work on policy that affects people's lives.

### FOR ALL NON DISABLED PEOPLE

We can check when we are invited to speak at events/ activities that are about, or impact on people, with learning disabilities, that people with learning disabilities are contributing to, if not leading the even/ discussion. If not, we can ask that this is rectified.

### FOR LOCAL AUTHORITY COMMISSIONERS

Co-ordinate a single place to share the excellent accessible and easy read resources.

Share ideas for 'earning money' to support the development of advocacy and self-advocacy.

### FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

Develop a clear brand for self-advocate produced resources, with a quality standard can be used to show that the service is being delivered by a self-advocate-led organisation.

# CHAPTER 6: EMPLOYMENT AND CONTRIBUTION

“Beware the soft bigotry  
of low expectations”

Noel Pearson

Noel Pearson is an Australian lawyer, academic, land rights activist and founder of the Cape York Institute for Policy and Leadership.



Having meaning and purpose are key to living a good life. It is important that we can all experience the sense of belonging that comes from feeling valued and respected for the contribution we can make. The opportunity to contribute may take many forms. When we undertake paid employment, the appreciation we experience may come in the form of the salary we earn, it may be positive recognition from colleagues and/or feedback from those we serve or whose lives we positively impact upon. Voluntary work also provides valuable ways to connect and contribute.

Whilst the focus of this chapter is primarily paid employment, we should not underestimate the value of identifying, elevating, and celebrating individual gifts, skills, and strengths. The following story, of Nicola and Lynn Elwell's experience of creative contribution, perfectly illustrates the opportunities available if we change our perspectives from challenges to opportunities, and from deficits to strengths.

Nicola didn't use words to communicate but those who knew and loved her understood her well. She didn't move independently and needed help to move both in her wheelchair, and to get around and about. Lynn, her mum, wanted to ensure Nicola had opportunities to connect and contribute. She focussed on Nicola's gifts and strengths.

One of Lynn's observations was that Nicola was very good at being still. Thinking about where this strength would be an asset, Nicola was supported to become a life model for art classes.

Thank you to Lynn Elwell for sharing this story. Nicola passed away some 18 years ago. Her memory lives on and the stories of her life still resonate powerfully.

# WE ASKED AND YOU SAID

There has been a consistent message over years of consultation, that people with learning disabilities want to contribute, to engage, to be included, valued, and respected. For many, this means gaining access to paid employment.

Here are some of things we have heard:

Good quality supported employment is a postcode lottery. It should be available to everyone with a learning disability through education and into adulthood.

Where reasonable adjustments are considered there is often a focus on physical access, rather than adjustments that would support the engagement of people with learning disabilities such as working interviews, job carving and adapted training and induction.

People do not think the Equalities Act is clear and enforced. It requires individuals to make a claim for discrimination when the costs and time involved are prohibitive.

There are no national targets for employing people with learning disabilities.

There is a lack of understanding about Access to Work and what this can fund for people with learning disabilities.

Traditional recruitment practices can make it difficult for people with learning disabilities to showcase their skills and talents for doing a particular job. For example, applications and selection methods may need literacy skills which are not required for the actual job. People need time to learn their jobs and show their worth.

There is a lot of information available for employers, but this does not seem to be making a significant difference to approaches to recruitment.

The benefit system is felt to be confusing and keeps changing. Some people are worried about losing their benefits that they had to fight hard for.

The education system is often not aspirational about what young people can achieve, and some people leave feeling unprepared for the world of work.

Some young people with a learning disability are not having the opportunity to do work experience with an external employer whilst in education.

## HUMAN RIGHTS FRAMEWORK

The right to freedom from discrimination is enshrined in Article 14 of the European Convention on 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 employment.

## ARTICLE 27 – WORK AND EMPLOYMENT

States parties recognise the right of persons with disabilities to work, on an equal basis with others, including the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realisation of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to among other things:

- Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions.
- Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances.
- Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others.
- Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training.
- Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment.
- Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business.
- Employ persons with disabilities in the public sector.
- Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures.

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

# HUMAN RIGHTS FRAMEWORK

- Ensure that reasonable accommodation is provided to persons with disabilities in the workplace.
- Promote the acquisition by persons with disabilities of work experience in the open labour market.
- Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

In addition to human rights frameworks, the Equality Act (2010) protects people against discrimination in the workplace at all stages of employment. This includes recruitment, employment terms and conditions, training, pay and benefits, promotion and transfer opportunities, dismissal or redundancy.

Evidenced by the low employment rates for people with learning disabilities, these supportive frameworks need to be more widely understood. This would potentially increase employers' confidence recruiting and retaining from the untapped talent pool of people with learning disabilities.

## WHY IT 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% but research shows as many as 86% want a paid job.

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 can cost only £75.

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.

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

# HUMAN RIGHTS FRAMEWORK

# IDEAS WE CAN WORK ON TOGETHER

Supported employment has for many years been a successful way of supporting people with learning disabilities to get and keep paid jobs.

This diagram from BASE (British Association for Supported Employment) illustrates how the approach works.



Supported employment is based on the following principles:

- Everyone who wants to work, can work in the right job with the right support.
- Everyone can make a positive contribution in the workplace.
- Jobs are real jobs, where wages are paid at the going rate with the same terms and conditions as other employees.

# SUPPORTED EMPLOYMENT

A supported employment model uses a partnership approach to help people find good jobs and careers, and helps businesses employ valuable workers. It is about good quality, person-centred support to find the right job for the right person and putting training and support in place to help them do a good job to the employer's standard. The model is called place, train and maintain as it takes the person and the potential employer through the process together from recruitment to retention. The process should be seen as mutually beneficial for the employer and the employee.

Supported Employment meets the needs of both jobseekers and employers through their job matching support. The aim of job matching is to ensure that employers get the right worker and people with a learning disability get the right job. This may involve either carving or designing jobs. Jobs can be 'carved' by selecting and combining duties from one or more existing jobs into a new position. Jobs can be designed based on an individualised match between the strengths and interests of an individual and the identified business needs of an employer.

Supported employment has a range of benefits for people with learning disabilities. It ensures that people are supported to be full and active members of workforces and wider communities, both socially and economically. Employment is a valued social role and becoming employed can help change negative perceptions, with wider positive consequences for the person and the wider community.

# IDEAS WE CAN WORK ON TOGETHER

The following ideas have been gathered from people interested in promoting the rights of people with learning disabilities to work and contribute to the communities in which they live.

- Develop a commissioning model for supported employment that works for people with learning disabilities. This will require partnership working across Department of Work and Pension (DWP), the Department of Health and Social Care (DHSC) and local authorities. This should build on DWP's Proof of Concept pilot where supported employment was co-funded across the local authority and DWP across 12 services and 9 local authority areas.

- There are now National Occupational Standards for Supported Employment practitioners and provision offering supported employment across education, DWP and DHSC. There is also a quality kitemark from BASE. All commissioned services should be required to gain the kitemark. In addition, all staff should be trained use supported employment techniques.

- People with learning disabilities their needs and priorities to be integrated into the Get Britain Working White Paper roll out including support to work and development of new welfare system.
- There is a need to raise the ambition within the education system starting with early years. Education and Health need to focus on what learning disabled children can achieve.

- Vocational profiles should be embedded in Education, Health and Care Plans (EHCP) from year 7 with an expectation of employment, utilising supported employment as necessary, as an outcome.
- Embed supported employment into the curriculum from age 14 so that all young people experience the world of work whilst in education.

- Large publicly funded organisations, such as NHS Trusts, should be accountable for the number of people with learning disabilities they employ. The Connect to Work programme started in 2025 using a Supported Employment model can help people with learning disabilities work with the right support.

- All advisors at Jobcentre Plus should be required to know and understand the principles and techniques underpinning supported employment and how to apply them in practice.
- There needs to be great reliance on evidence-based approaches that offer cost effective ways of supporting people with learning disabilities gain and maintain employment.

- There needs to be a parity of incentives to support employers taking on apprentices with a learning disability across programmes including supported internships, traineeships.

- Make sure that changes to welfare benefits mean that people with learning disabilities can volunteer and contribute without risking benefits. Building skills, confidence and community presence must be valued in its own right.



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

## Good example 1

The Disability Employment Charter calls for the government to act. It proposes a set of vital measures that, if implemented in a concerted manner, would substantially shift the dial on disability employment. By setting out clearly and simply the actions needed, it provides government with a road map for change as it develops the next phases of its National Disability Strategy. The Charter consists of nine areas of action. Each of the nine areas contain several specific asks that will help engender significant improvements to disabled people's employment outcomes.



## Good example 2

Project Choice is a Specialist Post-16 College providing work experience as well as a supported internship programme that helps young adults between the ages of 16-24 with disabilities, learning disabilities, difficulties and/or Autism gain work experience and improve employability and independence skills. Hft works with DFN Project SEARCH, and various other partners to run several supported internships in a variety of locations. Hft's role is as the Supported Employment provider. Every intern is supported by an Employability Coach to learn new skills while on their work placement. After the intern graduates, they receive 9 months support to seek and apply for a paid job, and ongoing support as needed once a paid job has been secured.

## Good example 3

Nationally there are supported employment projects are effectively helping people secure and keep jobs. An example of this is Strawberry Fields in Liverpool. NDTi have resources and examples to support the development of Employment Support for disabled people.

# WHO DO WE NEED TO ENROL/ENGAGE?

Strangely the current employment crisis in terms of the number of unfilled roles may require employers to be more creative in their approach to recruitment. This, in turn, may provide opportunities for the gifts and skill of people with learning disabilities to be recognised. What was considered unthinkable pre pandemic, the level of home working, online access is now the new normal. These opportunities should be grasped. There are many organisations BASE, NDTI, Nasen, Natspec, and DFN, among many others, campaigning for the same cause. It may be more effective to collaborate and speak with one voice on the important issue of paid employment.

## NEXT STEPS/FIRST STEP

We need to raise our aspirations for what people with learning disabilities can do when we consider their gifts and skill and how these may be put to good use for the benefit of all of us. As we become more aware of the implications of climate change and the economic hardship, we have also begun to look at our neighbourhoods and communities differently, looking to local resources and assets and people with learning disabilities should be an integral part of these deliberations. Our first step should be to build on the good examples detailed above.

### FOR SERVICE PROVIDERS

Organisations supporting people with learning disabilities should ensure that the support they provide builds opportunities for human flourishing and contribution. Everyone has something to offer, even if, on occasion, the person may be unaware of it themselves. It is the role of service providers and others to ensure every person has opportunities to contribute, through paid employment, volunteering, or other civic action.

### FOR GOVERNMENT

**The Good Lives Manifesto** There needs to be more accurate and available data on the number of people with learning disabilities in paid employment, including hours worked, collected nationally to support targeted investment and local commissioning making sure people with learning disabilities are equally included in employment support initiatives and not further disadvantaged.

**The ask:** 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.

## FOR GOVERNMENT

### The Good Lives

**Manifesto** States that the government should work with people with learning disabilities and their supporters to remove the barriers to employment and to share what is possible

**The ask:** Co-produce a benefits system that recognises everyone's right to an adequate standard of living and values individual's contribution and takes account of the additional costs associated with disability.

## FOR COMMISSIONERS

All local authorities should commission a supported employment service where the proportions of people who are in paid work would become an indicator of quality, human rights-based support.

## FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

Access to advocacy and peer support needs to reinforce increased aspirations through school into adulthood with an expectation of lives filled with meaning and purpose. People with learning disabilities and their families should be supported to use human rights frameworks to reinforce that such aspirations are based the realisation of existing rights. Sharing stories of success should sustain the vision that better is possible.

# 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.



# CONCLUSION

“Hope can remind us that there is nothing inevitable about the political and societal choices that diminish the lives of people with learning disabilities”

Katie Clarke and Katherine Runswick Cole ●

Much has changed since the first edition of the Good Lives Framework published in 2022. While covid is still a feature of our day to day lives, the restrictions associated with the pandemic that overshadowed the content of the first edition are, thankfully are a thing of the past. There is much we are still to learn from that period and the implications are still being felt and are yet to be fully realised. Only time and a period of reflection will reveal the full extent of the impact.

There has been an election and a change of government since 2022. LDE used the first edition of the Good Lives Framework to inform the creation of a Good Lives Manifesto the aim of which was to inform aspiring politicians and political parties of the need to address key issues facing people with learning disabilities.

The work of the manifesto has now been incorporated into this second edition. This document was always intended as a work in progress with new material added iteratively. This revised edition includes new ideas for things we can work on together as well as new inspiring good examples that help us consider what is possible. In addition, there is a new chapter on health for a good life.

There is still no sign of a national strategy for learning disabilities. But in that space, there is much we can do to inspire, create and provide allyship with each other. Times are tough, there is no getting away from it. As we said in the first edition, it would be easy, and justifiable, to experience anger and frustration at the situation we find ourselves in however, as Katherine Runswick Cole and Katie Clarke say

**“Hope is not something that can cancel out the outrage and anger we feel about the injustices people with learning disabilities face.**

**Hope for the future should not be used to excuse or diminish the responsibility of those who continue to perpetuate or tolerate these injustices.**

**But hope can remind us that there is nothing inevitable about the political and societal choices that diminish the lives of people with learning disabilities. There is nothing ‘about’ people with learning disabilities that mean that their lives have to be this way.”**

This still applies, now even more so. We have been heartened by the feedback we have received about the framework and about how individuals and groups have used it to help inform their thinking and action.

The document is only as good as we collectively make it. The more ideas and local innovations you share with us at LDE the more we can ensure the framework reflects not merely the challenges but also the best of who we are and how we can be.

We recommit to seek out and share examples where, through ingenuity and dogged determination, individuals, families, organisations, and allies have surmounted challenges and forged a path that others can follow.

Our ask is that you share this work with us so that we, together, can play our part in the movement to create a better tomorrow.



Learning Disability England

We would love to hear from you

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