GOOD LIVES: BUILDING CHANGE TOGETHER

PROLOGUE

Learning Disability England is bringing people and organisations together to create a movement for change where people with learning disabilities, families, friends and paid supporters come together on an equal basis.

As a membership organisation, we can be a national focal point where people can work together, engaging in a common cause; building a world where people with learning disabilities lead good lives.

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 frustrations, the irritations, and the heartbreak of individual and collective lived experience. Equally, we are fortunate to witness the green shoots of opportunity as courageous individuals, families, groups and paid supporters wrestle with some of the knotty issues that get in the way of individuals leading their best lives. A grant from Esmee Fairbairn Foundation has supported our work on this so far, significantly helping us get this far.

This aim of this document is our humble first effort to harness some of this energy and activity. To begin, again, to articulate clearly what people we have engaged with say they want and need to live well. To highlight the challenges that currently exist and to offer some hopeful examples where these have been overcome.

The aim of this document is to be both a starting point for conversation and, importantly, for action. We hope that this will be the first iteration and that this document evolves as we work together to plan, act and deliver a more hopeful tomorrow.

Please accept this as our invitation to engage in this collective endeavour. We look forward to working with you.

Change to Good Lives:
Building Change Together

ACKNOWLEDGEMENTS

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

A particular thanks goes to those who shared their tenacious work, offering the promise that better is not only possible but is a reality and, by doing so, treading a path that others may follow.

Thank you to everyone who shared their personal stories and agreed for those to be used to illustrate what is possible when we look to gifts and strengths.

Thanks also goes finally to Dr Sam Smith of C-Change for writing this report. Weaving together the varied threads of our work into this document.

CONTENTS

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)

IT HAS BEEN 20 YEARS SINCE VALUING PEOPLE – A NEW STRATEGY FOR LEARNING DISABILITY IN THE 21ST CENTURY ●, WAS PUBLISHED. IT WAS THE LAST COMPREHENSIVE NATIONAL POLICY STATEMENT FOR LEARNING DISABILITIES IN ENGLAND. WHILST MUCH OF THE STRATEGY STILL APPLIES, A GREAT DEAL HAS ALSO CHANGED IN THE INTERVENING YEARS. WE BELIEVE IT IS TIME TO UPDATE PUBLIC AND SERVICE ASPIRATIONS FOR PEOPLE WITH LEARNING DISABILITIES, TO MAKE THEM FIT FOR THE 2020S.

Our aim, with this document, is to develop something that local people can use as a template for how they go about changing things for the better. It may also be seen as a starting point for a new national policy that we hope will emerge over the next few years.

We have been helped in this effort by the fact that, despite the many struggles, there are good examples all over the country of individuals, families and services innovating and overcoming challenges and creating solutions to ensure people live good lives. We don’t need to reinvent the wheel or start from scratch. We believe we can use these examples to inspire each other to continue to build more and better opportunities for people with learning disabilities, their families, and our communities.

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

THE LANDSCAPE

Much of the work informing this document predates the arrival of the COVID-19 global pandemic. We continued our engagement activity as the virus spread through communities around the world. No other modern phenomenon has had such an impact on the way we live our lives. The pandemic has brought into sharp relief existing inequities and amplified them. We know, for example, that people with learning disabilities on average die significantly younger than the general population. They are also more likely to experience loneliness and social isolation and are significantly less likely to achieve educational qualifications, alongside a myriad of other social, health and economic disadvantages.

For several years, even before the pandemic there has been a developing awareness and growing public consternation at the plight of people with learning disabilities and/or autistic people trapped in assessment and treatment units and subject to abuse and neglect. The desperate nature of these situations was highlighted through a series of high-profile scandals and also by the failure to respond to these effectively. Pressure and momentum for change has been sustained through powerful and effective social campaigning, advocacy and lobbying. The Joint Committee on Human Rights conducted an inquiry into the detention of young people with learning disabilities and/or autism. Learning Disability England fully supports these efforts.

In addition to this important issue the pandemic has, in a wider sense, placed a spotlight on the structures, systems and processes that underpin how we live together, what we share and what we value. It became clear, very early on, that the impact of this crisis was not evenly distributed, as Damian Barr stated,

> “We are not all in the same boat. We are in the same storm. Some are on super-yachts. Some have just one oar”

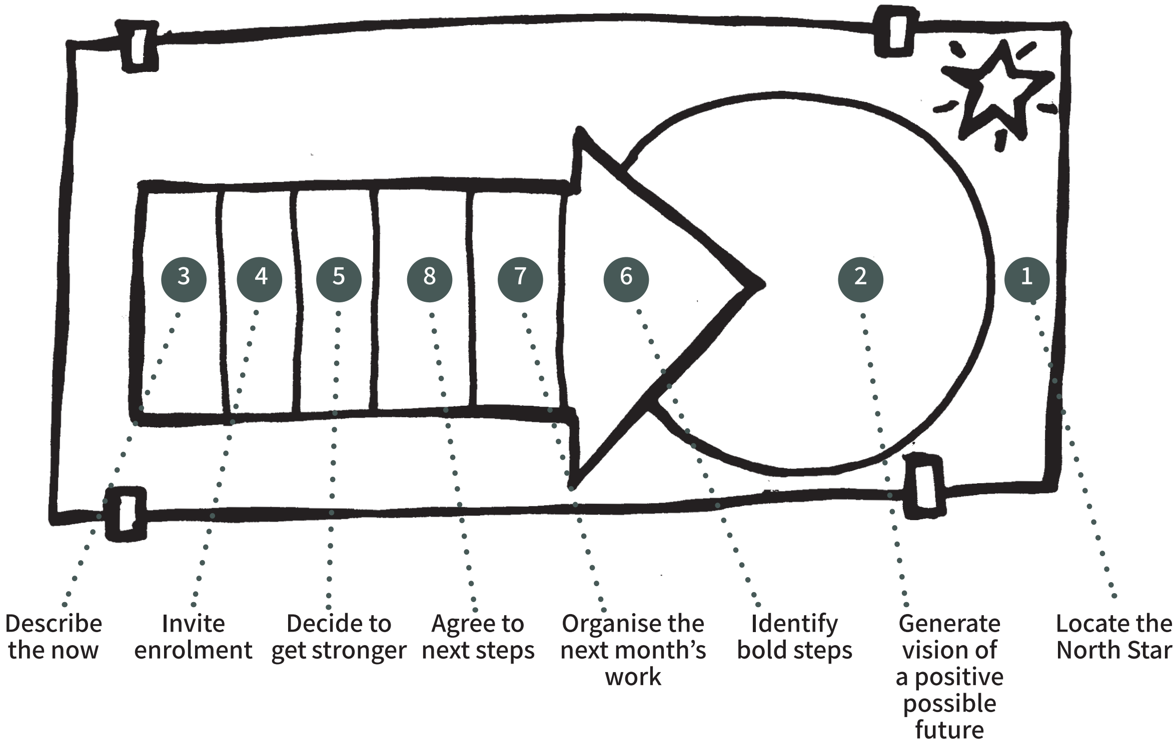
Disabled people, their families and carers have borne the disproportionate brunt of the pandemic. The impact of health inequalities and deficiencies in the provision of care for people with learning disabilities contributed to rates of death higher than the general population, particularly among younger adults with learning disabilities and Black, Asian Minority Ethnic people with learning disabilities. In addition, ongoing research highlights the impact changes to supports and services have had for people with learning and their families, a factor compounded by the lack of digital inclusion.

The average life expectancy for a male with learning disabilities was 61 years old, while for females it was 59 years old. This is compared to average life expectancy of 83 for males and 86 for females in the general population.

OUR PLAN

We wanted a structure to help to shape this work that felt inclusive and progressive. 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 a aspirational direction of travel and ask others to enrol to make the 'dream a reality'.



OUR PREPARATION

The groundwork for this 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 gathered all of this together and reviewed all the evidence and examples of what people said was important to them. We then convened, in February 2020, a meet up with a group of 40 self-advocates from across England. Through a process of discussion and debate, and drawing additional material from local networks, those issues were ranked and prioritised. The group also agreed a set of 'rules' to ensure the work was led by learning disabled people and not service system priorities.

Subsequent work involved reviewing the priorities with the wider membership which resulted in the addition of digital inclusion as an issue and relationships/connection being afforded a higher priority ranking.

Upon reflection, what mattered most to people with learning disabilities and families were issues relating to their rights as fellow citizens and as disabled people. It seemed appropriate then to use the United Nations Convention on the Right of Persons with Disabilities as a way of structuring and framing our document.

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 underlie 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

Given the current challenges it would be understandable if people felt overwhelmed. 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, using examples, illustrates possible ways to bridge these gaps. We also hope that it may be seen as 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”!

THE ROUTE

This work is rooted in collaboration and 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. This is what we have begun to set out in this document.

Key areas or themes have been highlighted as important by those we have worked alongside and engaged with. We have structured these into the following chapters, some of which are more expansive than others. 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 this point.

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 acknowledge that some key areas are not addressed directly in full chapter form, for example health and education, the experience of the Black and Minority communities. This is not an oversight, more a reflection of the discussions and activities to date, we know we have more work to do.

As our engagement continues and more debates ensue, this document will evolve. This imperfect version 1 reflects the first articulation of, what we hope will be, many more deliberations and actions to come.

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 a first step towards this end point. All we ask of you is your willingness to get involved.

> “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

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 during The Big Housing Conversations what was important to them about home and family life, 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.

A lot of people said everyone should be able to choose where they live and who they live with

They said this is their Human Right, the same as for people who do not have a learning disability

People said the law needs to work better

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

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 in 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.

Inclusion Europe explain more about Article 19 and how it works **HERE**.

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

- 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.

- The government needs to recognise the pivotal role of housing and create a more comprehensive and integrated national and local planning and policy framework for supported housing. This should be designed to ensure that supported housing receives an appropriate share of available resources and that local commissioners have access to the tools and information required to address changing needs.

- 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.

- A long-term sustainable, consistent housing benefit regime for supported housing should be created.

- 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.

- 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.

- Advocacy support should be routinely available for people who don't have family to support them to exercise their housing rights.

- 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.

- 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.

- 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

The Learning Disability and Autism Housing Network created a Learning Disability and Autism Housing Network Charter with the aim of providing, developing and promoting quality homes and housing services for people with a learning disability and autism.

> “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

The Home Ownership for people with Long term Disabilities (HOLD) scheme is very positive and it has been life changing for some people. If a person has a long-term disability, the HOLD scheme in England could help them buy any home for sale on a shared ownership basis (part rent/part buy). They can buy a share of their home (between 10% and 75% of the home's value) and pay rent on the remaining share.

> “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

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)

WHO DO WE NEED TO ENROL/ENGAGE?

As can be seen by the 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, including an understanding of the priorities of Black Asian Minority Ethnic people and 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

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 that will support 'needs led housing'.

In addition Government should create a more comprehensive and integrated planning framework for a range of housing options (including Supported Housing), update the rent standard for social housing and ensure stability in the welfare benefits system for tenants to maintain their home, particularly in relation to Housing Benefit.

FOR 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 digital world. For many the pandemic had made this worse, leading to feelings of isolation, anxiety, and mental health challenges. 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 supports want relevant information that makes sense to them at the same time as everyone else

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

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

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

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

Accessible information is necessary for people to keep themselves healthy, safe and well – particularly during the pandemic

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

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:

- A government-wide communications plan for making sure information is available quickly, meets accessible standards, is co-produced 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, different languages and more.

- Dissemination that is supported by a national co-production 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

Every two weeks since the start of lockdown Learning Disability England has held an online zoom session for self-advocacy, family and community organisations.

> “ 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

Good Things Foundation worked in partnership with AbilityNet and Digital Unite and was supported by Learning Disability England, the Voluntary Organisations Disability Group and other disability and digital inclusion organisations.

Digital Lifeline has seen more than 150 grassroots community partners and others distribute over 5,500 devices with data and offer both face-to-face and remote support to help recipients learn how to use their device safely and confidently.

Studies have shown that technology can help people with learning disabilities reduce feelings of loneliness and support their mental health and wellbeing.

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 need 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 has been 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 Government should ensure that people with learning disabilities are included in digital inclusion projects including access to equipment, WiFi 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 WiFi 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 connect 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 specialists 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 a Think Tank on social care . 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.

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 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

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.

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 would look 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.

> “I really enjoyed the workshops, I really feel it is just what I needed to refocus and re-energise given the current climate we are in…now is the time to bring the principles of REACH to life!”

Team Leader, Kent

GOOD EXAMPLE 2

Learning disabled people recognise the challenges within the system and, when afforded the opportunity, create solutions that work for everyone. Greater primacy needs to be given to voice and views of those who draw on support. The LDE Social Care Think Tank is a good example of the positive potential when those whose voices are seldom heard are given a platform.

VIEWS FROM THE THINK TANK

Having good quality support is an important part of living a good life

People thought meaningful and positive relationships between staff and the people they support were important

Everyone thought working with people you liked, trusted and respected made living a good life easier

Having support that understands, values and listens to you makes life better

GOOD EXAMPLE 3

Helping People Thrive, Stories and Lessons in Transforming Care brings together stories and critically the voices of people who have previously lived in Assessment and Treatment Units and have since successfully built a life outside those services. The stories are shared to inspire as well as support practitioners understand the critical elements in success for all the people sharing their stories.

KEY MESSAGE IN THE PUBLICATION

> “We need to know what is happening that is different in places where the NHS, Councils, housing and care providers and families are helping people to thrive”

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 Future. Ensuring the voice and views of learning disabled people contribute to calls for more responsive, person led social care support.

VIEWPOINT

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

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 draw on 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

Build on the commitments made in People at the Heart of Care white paper in real partnership with people who draw on support with particular regard to the different life experiences of people with learning disabilities.

Regulators need to redefine the measure of what good looks like, ensuring the views of those who draw on support have primacy.

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 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. For many, the pandemic had made these difficulties worse, leading to feelings of isolation, anxiety, and mental health challenges. 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 were not prioritised in the pandemic response, particularly for people living in congregate settings

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

Withdrawal of support left families struggling, unpaid 'carers are financially underpaid and emotionally under supported'

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

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.

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.

You can find more information about these rights HERE

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, 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.

- 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.

- REACH standards adopted as basic standards for supporting good lives and underpinning all service provision.

- 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 Bed Times guide and a Manifesto for an Ordinary Life.

GOOD EXAMPLE 3

The British Institute of Human Rights (BIHR) promotes change through human rights by supporting people and organisations to use human rights advocacy and approaches in their everyday life to achieve positive social change. They work with people, with communities and with public bodies to develop greater understanding of the power and potential of human rights to transform lives.

GOOD EXAMPLE 4

Think Local Act Personal place an emphasis on building people’s resilience and social connections using asset-based practice; building social networks, encouraging membership of community groups, creating opportunities for social interaction based on active contribution. They also encourage social workers to change the workforce culture to one that is ‘strengths-based’, promoting wellbeing, early intervention and prevention.

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

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.

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

- 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

The 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. In July 2020 the researchers spoke to staff and members of 11 self-advocacy groups, representing all regions of England, to find out what they had been doing to support members during lockdown.

The breadth and depth of their work during the pandemic was impressive. Self-advocacy groups responded very quickly, moving much of their work online while also providing essential offline support, and face-to-face practical help where required. The research showed how and where self-advocacy was 'filling in the gaps' left by other services.

> "So I've had to spend ages looking for the accessible copy, easy read copy, and I'm like thank god for that, because I can truly understand it. Because from the official one you're like, I was like what does this truly mean? ... This is the thing, it's like in a pandemic you shouldn't have to ask for something to be made accessible" Self-advocate

GOOD EXAMPLE 2

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 3

The Keeping People Connected project was co-designed and delivered by 12 local community organisations across Cumbria and the North East, in response the first wave of the Covid 19 pandemic. The North East and Cumbria Learning Disability Network and Inclusion North provided leadership and co-ordinated the project.

Keeping People Connected was designed to help people with a learning disability or autism to understand information from the Government, connect with others to avoid isolation and get the support needed for other things in their lives.

Keeping People Connected was unique in so far as it enabled support at right time preventing issues escalating. There were no eligibility criteria, and while it was aimed at people with learning disability and/or autism there was no formal assessment to gain access. It was delivered entirely by Community Voluntary Sector organisations around North East and North Cumbria.

WHO DO WE NEED TO ENROL/ENGAGE?

As can be seen by the range of ideas we can work on together some, such the creation of a national network alongside national decision makers 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

Support the development of self advocacy national networks through the disability strategy. Ensure self advocates or user led organisations are a part of all work on policy that affects peoples 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 event/discussion. If not, we can ask that this is addressed.

FOR 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 that can be used to show that the service is being delivered by a self-advocate-led organisation.

Look at how voice or advocacy groups are representing all local people including people with high support needs and from Minority Ethnic Communities ●

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.

There is a growing movement to challenge traditional assumptions of desired characteristics, with a greater emphasis being placed on valuing diversity.

This challenge is particularly acute when it comes to people with learning disabilities having access to good quality employment. Less than 6% of people with a learning disability access paid employment. The type of work they do secure is often low paid and insecure. There are some very welcome exceptions to this norm, such as the recruitment of George Webster, a young man with a learning disability, as a children's television presenter. However, with a reported 1,102,000 unfilled job vacancies in the United Kingdom in August 2021, it is long past time that people with a learning disability are viewed as part of the solution for building a stronger and fairer economy.

Michael Marmot's report, 'Health Equity in England: The Marmot Review 10 Years On', highlights the huge health inequalities that exist for people with learning disabilities (among other groups); showing life expectancy in England has stalled. One of the six actions highlighted under 'early intervention to prevent health inequalities' was the need to "create fair employment and good work for all." Suggesting the need for low employment rates amongst people with learning disabilities should be addressed as a matter of some urgency.

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 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 discriminationwhen 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 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.

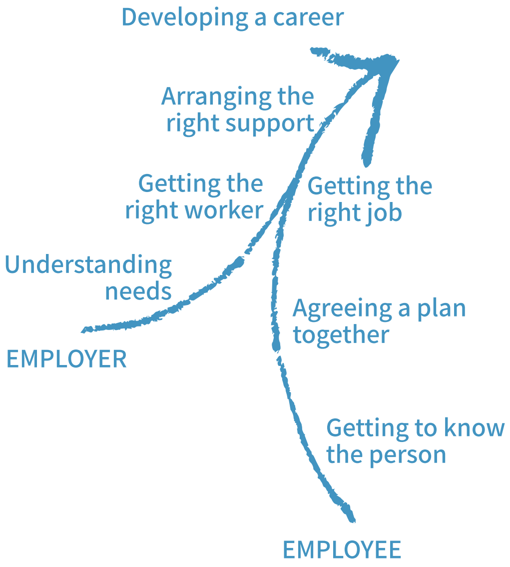
HUMAN RIGHTS FRAMEWORK

IDEAS WE CAN WORK ON TOGETHER?

SUPPORTED EMPLOYMENT

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.**

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. An 18-month DWP 'trailblazer' was announced in March 2020 which should be tracked to see if it benefitted people with learning disabilities.

- 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 to use supported employment techniques.

- 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.

- Embed supported employment into the curriculum from age 14 so that all young people experience the world of work whilst in education.

- 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.

- 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.

- Simplify the Adult Social Care Outcome Framework (ASCOF) indicator so that it gives a more accurate figure for the numbers of people with learning disabilities in employment, paid at least the National Living Wage for all hours worked. Health and Well-being Boards should assume responsibility for monitoring this.

- Large publicly funded organisations, such as NHS Trusts, should be accountable for the number of people with learning disabilities they employ, ensuring they meet NHS Long Term plan targets.

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

- There needs to be great reliance on evidence-based approaches that offer cost effective ways of supporting people with learning disabilities to gain and maintain employment.

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

GOOD EXAMPLE 1

In the 2016 Mencap Here I Am campaign , Vijay describes his journey as a young ambassador and his greatest wish that everyone with a learning disability, who wants to work can.

> “My hope for the future of people with a learning disability is to make sure they are getting into employment.A lot of people with a learning disability don’t get the chance to be able to get a job. People should offer them a work trial or work experience so that they can develop their skills and tell their employer,‘I can do this as well’. It is important that they are not left out.Us people with a learning disability can also do that job”

GOOD EXAMPLE 2

Project Choice is a Specialist Post-16 College that provides 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. The College is NHS-based within Health Education England.

It provides internships within healthcare settings and other NHS partner organisations, creating supported environments and helping to get Interns ready for the working world.

GOOD EXAMPLE 3

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.

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 skills and how these may be put to good use for the benefit of all of us. The pandemic has required us to reconsider who our 'key workers' really are, our shop workers and shelf stackers, our nurses and doctors, our teachers, refuse collectors and delivery drivers. These are the people we cannot do without when times are tough. We have also begun to look at our neighbourhoods and communities differently as people co-ordinate and support each other to get through the worst of times. Volunteering and contributing to the wellbeing of others has become more common currency as we have been forced to lock down, isolate and in some cases shield against the Covid19 virus.
As we move beyond the pandemic, we should endeavour to retain those positive aspects of our humanity that came to the fore and reinforce them to build forward better than before. 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 to ensure every person has opportunities to contribute, through paid employment, volunteering, or other civic action.

FOR GOVERNMENT

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, the NHS Long Term Plan priorities and local commissioning.

There is a requirement for national investment in supported employment with local delivery based on agreed quality standards (such as the BASE supported employment standards).

Engaging with employers and people with learning disabilities to develop supported employment service specifications.

Access to Work support and welfare benefits need to consistently support working.

FOR COMMISSIONERS

All local authorities should commission a supported employment service where the proportions of people who are in paid work would become a performance indicator for support providers.

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 such aspirations that are based on the realisation of existing rights. Sharing stories of success should sustain the vision that better is possible.

CONCLUSION

> “Hope involves a vision of the good world that might ensue, and, often at least, actions related to getting there”
>
> Martha Nussbaum

Martha Craven Nussbaum is an American philosopher and the current Ernst Freund Distinguished Service Professor of Law and Ethics at the University of Chicago.

Twenty years ago Valuing People was published. It stated,

> “People with learning disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with learning disabilities must no longer be marginalised or excluded”

It set out a plan for how the government would ‘provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities.’

Twenty years on we are in the middle of a global pandemic, and it feels as though everything is disrupted and dislocated. However, despite this, some things remain the same. We know that the impact of the pandemic has not been experienced equally across communities. Disabled people, and learning disabled people in particular, have been disproportionately negatively impacted by the pandemic. Existing inequalities have been magnified. The clarity of vision and purpose articulated by Valuing People provided a focus for much progress and without an equivalent it can feel that at best we are standing still, if not slowly drifting backwards. It would be easy, and justifiable, to experience anger and frustration at the situation we find ourselves in however, as Kathryn Sikkink (Kathryn Sikkink is an author, human rights academic, and scholar of international relations) notes,

> “Anger is not sufficient to maintain motivation over time; you also need to have hope and to believe that you can make a difference”

We believe concerted effort is needed, and this report is our first contribution towards this. We would dearly love for this document to be useful, and for it to develop into something that local people can use as a template for how they go about changing things for the better. We also hope it may be seen as a starting point for the discussion of a new national policy, a Valuing People: The Next Generation, if you will, that should emerge over the next few years.

Our commitment is that we will actively 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.

LDE

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