

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 person's 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.