

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.