



Brighton and Hove Speak Out

Moving Forward Needs Assessment 2020-21

Literature Review – Report by Jim Simpson

1. Summary overview

Speak Out is planning its future and how best it can deploy its competencies and resources to helping learning-disabled people in Brighton and Hove. There are choices about which issues to tackle (e.g. getting good health and social care, transitions); and what methods or models to deploy (e.g. case-based advocacy; group-based advocacy; other support methods). Speak Out also wants to be informed about the many needs issues faced by people with learning disabilities (PWLD) and this report highlights many of these needs. For instance, people with learning disabilities do not get good enough treatment from the NHS. Social care is not enough to meet people's needs. Loneliness, social isolation and poor mental health are worse for learning-disabled people. PWLD are not general part of the workplace. Also the covid-19 epidemic has exacerbated many of these problems. This report gives some summary details of these needs issues and Speak Out's work in order to inform Speak Out's 'Moving Forward' strategic evaluation and planning process. This is a brief review of literature summarising a lot of topical issues. There is not the space to cover every topic particular to learning-disability. Several footnotes provide links to sources of further information.

2. Setting the Scene

Speak Out has a long history of providing a range of advocacy, support services and activities for and with PWLD in Brighton and Hove. Speak Out provides:

- One-to-one advocacy casework - top issues supported with clients are: 1. Accessing Social Care 2. Housing problems 3. Health & Mental Health 4. Transitions for young people 5. Rights of parents with learning disabilities
- Drop-ins - in 3 parts of the city
- Consultation events
- Self-advocacy groups
- Learning disability voices network
- A helpline and Zoom drop-ins - Covid-19 epidemic specific support (since March 2020)

Speak Out currently works with about 400 people a year. In addition to this, the wider learning disability community benefits from Speak Out's online resources, consultation, group advocacy and training work. Also health and social care workers and the community in general benefit from Speak Out's work.

This diagram below¹ from Speak Outs Impact report shows what Speak out currently provides in more detail.



In the future Speak Out wants to expand its reach in order to meet additional needs and to do more to support PWLD. Before deciding upon any new or changed strategic objectives Speak Out wants to review the broader needs of PWLD.

Speak Out and other support agencies cannot meet the enormous advocacy, social care, support, health and other needs of PWLD. Demand for help, advocacy and support far outstrips the supply of services and support mechanisms. With this in mind, Speak Out wants to support PWLD and the LD community in the best ways possible using its organisational capabilities.

The rest of this report will look at the needs issues and demography of PWLD in order to inform Speak Out's deliberations about short and long term strategy.

¹ Speak Out. *Speak Out Impact Report 2019 – 2020*. Accessed January 11th 2021
<https://www.bhspeakout.org.uk/impact-report/>

3. The disadvantages endured by PWLD

We know that PWLD endure many disadvantages and discrimination – discrimination that can be indirect and unconscious bias that is hard to see, through to hate-crime and bullying. Some of these issues are shown below as a starting point to unravelling needs issues.



These introductory facts highlight why having a learning disability can mean that many other problems and difficulties have to be faced that are nothing to do with a learning disability. Problems such as less-good medical care or more exposure to hostility or aggression are societal inequalities. PWLD need to be supported to deal with these issues. Also attitudes and practices in the wider community need to change so that PWLD can have the same access to services as everyone else and having their rights secured.

4. Demographics

In the UK there are around 1.5 million people with a learning disability. In Brighton and Hove it is estimated that there are 5,860 adults² with a learning disability. In the region of 23% of these have moderate to severe learning disabilities where the person concerned is entitled to receive statutory social care support. The number of people in the city with a learning disability is rising year-on-year. This is partly due to the rising population, but also due to increasing levels of some conditions such as ASD (Autism Spectrum Conditions) and other reasons.

² Brighton and Hove City Council *Draft Strategy, Learning Disability* (2020). Note: data is drawn from the PANSI database (Projecting Adult Need and Service Information).

The 5860 group of people with a learning disability includes those with mild, moderate, and severe learning disabilities.

5. Managing day-to-day to life - 'self-building' or stuck?

"Social care provision is becoming more personalised for disabled people in the UK. Increasingly people in need of social care are being asked to take more responsibility for organising care, support, work and activities, what we are terming 'self-building' daily lives or 'self-build social care'."

The quote above is from an extensive study³ that looked at the idea of how learning-disabled people 'self-build' their lives. The research explains that there has been a long-term reduction in social care budgets and a tightening of eligibility criteria. This means that individuals need to self-build their lives. The research says that we need to 'understand how to support individuals and groups to self-build networks of support and learn to succeed in their communities'.

Learning-disabled people in the UK are being asked more and more to manage their own lives. They need help to do this and the value of advocates as helpers and enablers is more important than ever. However most independent issue-advocacy cannot provide this kind of life-skills support. The report conceived three essential building blocks for self-building lives:

- PLANNING THE ESSENTIALS: finding information and support; getting heard
- MANAGING THE DAY TO DAY RESPONSIBILITIES: running a home; benefits and money; getting around; feeling safe
- FINDING MEANINGFUL THINGS TO DO: groups; time with friends and family leisure; work and volunteering

Appendix two at the bottom of this report shows a picture and diagram that explains this model more. The research and the report recommend strongly that advocacy and self-advocacy is critical to self-building lives. Also the research emphasises how advocacy and self-advocacy can help 'build networks of peer-support with other self-advocates in the community'⁴. The self-building lives approach can help people to have more fulfilling lives, build independence and avoid crisis. People can avoid being stuck, alone and unhappy if a self-building approach is designed, managed and resourced well. During the Covid-19

³ Coverdale, Hall et al at Universities of Southampton and Dundee, *Self-building Our Lives, Social Care Research Report*. 2020. Page one. Accessed January 16th 2021 [#SelfBuildingOurLives - News](#)

⁴ *Ibid* 3 Page three

epidemic some self-advocacy groups have been filling a support gap but only at a minimal level, and without the resources for this kind of self-building and life-building work.

6. Health

Most NHS websites and sources of information for healthcare staff that deal with learning disability now routinely remind doctors and nurses that PWLD die younger and suffer more from illnesses and conditions that are treatable. Also many of these conditions and illnesses are preventable such as diabetes. This is a problem that the NHS is trying to tackle, and it is not a simple set of problems to fix. Landmark studies into the premature death of people with learning disabilities brought to public attention the fact that the lifespan of PWLD is shorter and that this needs to be investigated in more depth and systematically remedied. A report on NHS digital⁵ shows the following:

- Females with a learning disability had a life expectancy **18 years lower** than females who did not have a learning disability (**65 years compared to 83 years**) in 2017-18.
- Males with a learning disability had a life expectancy **14 years lower** than males who did not have a learning disability (**66 years compared to 80 years**) in 2017-18A

Hospital Care

Poor examples

Upsetting examples of compromised patient safety were found across all hospitals. In one case, a patient who had problems making himself understood was sent home by Accident & Emergency staff who incorrectly thought he was drunk.

In another, abnormal test results were not acted upon because staff assumed they were due to the patient fiddling with the equipment. The patient deteriorated rapidly and later died. On a simpler level, another patient with learning disabilities noticed that the refreshment trolley often passed her by.

Treating people differently

We found many hospital staff thought people with learning disabilities needed to be treated “just like everyone else” and were reluctant to label them as “different”. While this might be true for the level of care that everyone expects, it’s clear that people with learning disabilities have specific needs. If these are ignored, that level of care falls.

A poor understanding of how to deal with people who had issues with mental capacity, for example, results in compromised treatment.

⁵ NHS Digital *Health and Care of People with Learning Disabilities: 2017-18*. Health and Social Care Information Centre. Accessed January 14th 2021. [PowerPoint Presentation \(digital.nhs.uk\)](https://digital.nhs.uk)

National Institute for Health Research funded study⁶ found inconsistency in hospital care with some good examples of differentiated care for PWLD but poor examples also as the quote in the box demonstrates.

During the pandemic urgent care has come under the spotlight as deaths due to Covid-16 was at six times the national average amongst PWLD. Mencap⁷ have highlighted important changes needed to emergency admissions. For instance, health trusts need clearer guidance so that carers and advocates can accompany patients with a learning disability in ambulances; hospitals need to be shown what reasonable adjustments need to be made in times of crisis; and learning disabled patients need to be high up the priority list for vaccination in view of the shocking deaths-rate.

Support for learning-disabled people in the health system is also being damaged by a shortage of learning disability nurses. NHS digital reports a 40% drop in the number of registered LD Nurses in NHS posts from 5,368 in 2010 to 3,223 in 2020⁸.

Primary care:

Improvements to the health and wellbeing of PWLD cannot be achieved without the expert input of doctors and other health professionals. Yet still many learning-disabled patients are not made aware that they can book a double appointment; are entitled to 'reasonable adjustments'; and can get additional checks as part of an annual health check⁹.

There are some improvements being made in healthcare services for PWLD. For instance 55.1 per cent of patients with a learning disability (in the UK) received an annual learning disability health check in 2017-18, an increase from 43.2 per cent in 2014-15. Here healthcare managers are realising that early detection of conditions and providing additional support to patients with a learning disability is a pre-condition to combating health inequalities.

In Brighton and Hove only 36% of people with learning disabilities¹⁰ are getting the GP Health Check.

This is clearly not sufficient, and it is evidence of inadequate adjustments being made in primary health to support patients with a learning disability that can start to tackle

⁶ The Conversation. *People with Learning Disabilities are at Risk in Hospital* (2015) Accessed January 14th 2021 [People with learning disabilities are at risk in hospitals \(theconversation.com\)](https://theconversation.com/people-with-learning-disabilities-are-at-risk-in-hospitals)

⁷ Mencap. *My Life My Health, barriers to healthcare for people with a learning disability during the pandemic*. 2020. Accessed January 15th 2021 https://www.mencap.org.uk/sites/default/files/2020-12/MyHealthMyLife_COVID%20report.pdf?utm_campaign=1659437_Campaigners%20Covid%20report%20Jan%202021&utm_medium=email&utm_source=dotmailer&dm_i=4P14,ZKFH,2UTNL3,4GDKS,1

⁸ Learning Disability today. *Nurses not Hearses Campaign – addressing the shortage of learning disability nurses* Accessed 14th January 2021 [Mencap campaign to address the shortage of LD nurses \(learningdisabilitytoday.co.uk\)](https://learningdisabilitytoday.co.uk/mencap-campaign-to-address-the-shortage-of-ld-nurses)

⁹ Gov.uk. *Annual Health Checks and People with learning Disabilities*. 2016. Accessed January 16th 2021 <https://www.gov.uk/government/publications/annual-health-checks-and-people-with-learning-disabilities>

¹⁰ *Ibid* 2

substantial health inequalities. With good primary care in clinics and surgeries it is less likely that learning-disabled people will suffer from avoidable or treatable conditions and therefore be healthier. Furthermore, better diagnosis, treatment and support can go some way to driving down the shocking statistic of 1200¹¹ or more avoidable deaths a year amongst people with learning disabilities.

7. Covid-19

Speak Out set up a helpline when lockdown happened in March 2020. Speak Out's case records - only for the helpline over March 2020 to December - tell us what PWLD were needing support with.

Speak Out 9-month figures, Helpline only *:			
Support around anxiety	179		17%
Support around isolation	648		62%
Mental health and well being	84		8%
Other issues (health, benefits, other)	48		5%
Other corona-virus related	81		8%
Cases-issues total	1040		

* more details on these figures can be found at Appendix 1.

We can see from this data that the Covid-19 pandemic has exacerbated many difficulties that were worse for PWLD before the pandemic crisis and are worse still during the crisis. Speak Out's reporting on its support work has stated::

'it (the Covid-19 pandemic) has highlighted pre-existing inequalities in access to service, support and community. The societal, economic and health barriers faced by people with learning disabilities have been magnified.'

PWLD are more isolated and they have to fight harder to get friends and be in social networks of any kind. The helpline is dealing with many anxious people and with mental health problems that is twice the rate in the population as a whole. The Covid-19 epidemic is proving to be doubly tough for people with learning disabilities.

¹¹ Mencap. *Concerns over lack of clinical training causing avoidable learning disability deaths*. 2018. Accessed January 16th 2021 <https://www.mencap.org.uk/press-release/concerns-over-lack-clinical-training-causing-avoidable-learning-disability-deaths>

8. Mental Health

‘Mental health problems can affect anyone at any time and may be overcome with treatment, which is not true of learning disability’ ‘some studies suggest the rate of mental health problems in people with a learning disability is double that of the general population’

This information¹² above tells us that mental health needs to be looked at with great care and attention. Often learning-disabled people are perceived by other people to have mental illness or other mental health problems. Learning disability and mental health are regularly and wrongly confused or conflated. This can lead to poor diagnosis and can make the problem that the person is enduring even worse. People with learning disabilities are more vulnerable to mental health problems than the general population¹³. There are several contributory risk factors¹⁴ that can make learning-disabled people more prone to short-term and enduring mental health problems. These include:

- Biological factors - Pain, physical ill health and taking multiple types of medication can all contribute to poor mental health
- Negative life events - People with a learning disability may be more likely to experience deprivation, poverty, abuse and other negative life events earlier on in life
- Fewer resources – Lack of social support and reduced coping skills are associated with depression and anxiety in people with a learning disability
- Other people’s attitudes – Stigma and discrimination can become internalised, which can result in psychological distress.

¹² Mencap *learning disability explained, research and statistics, mental health*. Accessed January 16th 2021.

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/mental-health>

¹³ Mind charity *Information support*. 2016 Accessed January 16th 2021 <https://www.mind.org.uk/information-support/guides-to-support-and-services/learning-disability-support/overview/>

¹⁴ *Ibid* 11

9. Transitions

The transition into adult life is especially important to people with learning disabilities – and far more challenging. Change is often sudden and profound, such as leaving a school or college or changing accommodation. This can be complex, un-settling and a time of heightened anxiety. As such, ‘transitioning’ therefore needs careful planning and management involving the young person and their families and carers.

Planning for the young person’s future is supposed to be about the young person’s need, wants, talents, goals, hopes and aspirations rather than a focus on a medical model of disability and lack. This excerpt from the SEND Code of Practice¹⁵ makes the process plain:

High aspirations are crucial to success – discussions about longer term goals should start early and ideally well before Year 9 (age 13-14) at school. They should focus on the child or young person’s strengths and capabilities and the outcomes they want to achieve.

However all too often planning starts late and becomes focussed on what could be available and the cost, rather than focussing on the young person’s aspirations and the quality of a service/support activity that is required to help them achieve and flourish. Furthermore a medical-model approach can also lead to a focus on what is lacking, what is ‘wrong’, and what can be socially or educational proscribed for young person.

Speak Out has provided a small-scale transitions advocacy project to help your people to deal with some of the complexities and choices that they face in making a transition. Isolation may well be a worry if the young person only has friends at the school or college they are leaving. Education can be used as a holding pattern up to 25 years where the young person is experiencing the same activities, at the same level, repeatedly over some years. Independent living options are limited and those with a stable background will have a lower priority of access. This is an on-going barrier to change. Finding work or work-placements will be hard.

As this quote below illustrates, parents and carers find their ability to help their loved one also to be a challenge:

¹⁵ Preparing for Adulthood *Introduction to Person-centred Planning Tools*. 2020. Accessed February 1st 2021 [Introduction to Person-centred Planning Tools \(preparingforadulthood.org.uk\)](https://preparingforadulthood.org.uk)

"It feels like there's no information until you've started the process, and there doesn't seem to be a central place to find out about living options, perhaps that's because there aren't any for my child right now".

- Parent

Making good transitions also emphasises how important the 'ecology' or systems of relationship and support are in enabling young, learning-disabled people to move forward. For instance, Jacobs et al (2018)¹⁶ systematically reviewed research into transitions. They identified the fact that: 'The family appears to be the main support system for young people, highlighting the need for more substantial support for families in advocating and caring for their children'. Their research also highlighted the difficulties that families have in influencing commissioners despite the public service rhetoric of service user and carer involvement. They point out: 'Families and service users seem to have very little involvement in "wider" decision making such as service commissioning'. Similarly, this review identified: 'a lack of understanding of organisational and political decision making by families.'

The importance of transitioning to adulthood and leaving the education system is such a profound and important stage in the life-course of young learning-disabled people. It is essential that young people and their families are helped and supported as well as involved in the wider choices, opportunities and experiences that can be put to helping young learning-disabled people have good lives.

10. Relationships

Friendship and social participation are especially important to people with learning disabilities for three reasons¹⁷ at least:

¹⁶ Jacobs et al, *Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis*. J Appl Res Intellect Disabil. 2018;00:1–21. <https://doi.org/10.1111/jar.12466>

¹⁷ Mencap. *Why are friendships important to people with a learning disability* Accessed January 14th 2021 [Learning Disability - Friendships and Socialising Stats Mencap](https://www.mencap.org.uk/publications/learning-disability-friendships-and-socialising-stats)

Note: this source contains reference to, and synthesis of, many research studies and findings that contribute to the statements and claims made by Mencap

- **Happiness and confidence:** an active social life builds up confidence, and helps people feel happy and fulfilled. In turn, this enables people to try new things, have fun and learn skills as confidence grows through experience.
- **Reducing loneliness:** loneliness is shown to be harmful to physical and mental health with conditions like depression, high blood pressure and higher mortality directly linked to loneliness
- **Better health:** evidence therefore points towards better relationships being linked to better health and wellbeing.

Friendship and social contact are also a gateway to leisure pursuits and people with learning disabilities are not taking as much exercise in their leisure time as the population in general. Mencap's systematic review of research says that:

- Adults are recommended to take part in 150 minutes of moderate aerobic exercise per week (NHS, 2018). The Active Lives Survey found that only 43% of people with a learning disability do at least 150 minutes of exercise a week, compared to 67.4% of people with no disability. 44% of people with a learning disability took part in less than 30 minutes of exercise a week (Sport England, 2018)
- Adults with a disability or long-standing illness were found to have lower engagement in the arts, heritage sites, museums and galleries (DCMS, 2018)
- Positive direct contact through leisure activities can also help to challenge negative attitudes associated with learning disability (Scior & Werner, 2015).

Having a learning disability and making friends is difficult. PWLD don't have as much social contact as they would like. The Adult Social Care Survey in Brighton and Hove asked social care clients in Brighton and Hove¹⁸ if they had enough social contact:

- 40% of aged 18-64 say they have as much social contact as they would like.
- 51% of over 65's say they have as much social contact as they would like.

11. Discrimination and bias

Undoubtedly PWLD suffer more from various forms of discrimination and bias. They are more likely to report being bullied or experience hostility. How people with a learning disability are treated by others is getting better in some respects¹⁹.

- In 2000, 37% of disabled people felt that there was a lot of prejudice around
- In 2017, 32% of disabled people felt that there was a lot of prejudice around disability

¹⁸ *Ibid* 2

¹⁹ Scope. *Disability Perception Gap (2018)*. Accessed January 13th 2021. [Disability facts and figures | Disability charity Scope UK](#)

Attitudes to disabled people can be subtly problematic though. Using the same data as above shows what is being called a 'disability perception gap'²⁰ appearing.

- In 2000, 37% of disabled people and 34% of non-disabled people felt that there was a lot of prejudice around disability
- The gap trebled by 2017, with 32% of disabled people and 22% of non-disabled people feeling there is a lot of prejudice against disabled people.

What we have here is the general public thinking that prejudice against disabled is lower at 22% whilst disabled people who are experiencing prejudice see prejudice as higher at 32%. Another example of a bias against PWLD is shown by the research below. Here²¹ parents show an unsympathetic view of children with a learning disability.

The British Social Attitudes Survey in 2009 found that just 41% of parents would feel very comfortable if their child had a classmate with a learning disability, compared to 76% for physical and sensory disabilities. This highlights a key problem: on the whole people say that those with a learning disability should be treated equally, but at the same time many behave in subtly prejudiced ways which in fact reinforce negative stereotypes.

Discrimination can be subtle and not even known to the person. Unconscious bias or implicit bias describes how all of make quick, unconscious judgements about people some of which might be unhelpful stereotypes.

12. Poverty and Unemployment

People with learning disabilities, and disabled people in general are poorer than most are more likely to struggle financially. This is for many reasons. It is simply more expensive to have a disability – on average £583 extra a month²², and far more than this for people who need additional support to meet basic care needs and maintain their independence. Also most people with learning disabilities are not working and therefore dependent upon

²⁰ Ibid 6

²¹ The Conversation. *Are Attitudes changing to the 1.4 million people in the UK with a learning disability (2015)* Accessed January 14th 2021 [Are attitudes changing to the 1.4m people in the UK with a learning disability? \(theconversation.com\)](https://theconversation.com/are-attitudes-changing-to-the-1.4m-people-in-the-uk-with-a-learning-disability/)

²² Scope. *The Disability price tag 2019*. Accessed January 13th 2021 [Disability facts and figures | Disability charity Scope UK](https://www.scope.org.uk/disability-facts-and-figures/)

benefits. Approximately 8 out of 10 working age people with a learning disability have a mild or moderate learning disability, but less than 2 in 10 are in employment²³.

13. Other needs issues

Covid-19 and digital inclusion:

The isolating conditions of the pandemic has resulted in everyone having to find ways of living their lives at home and from home. So many aspects of our lives that can take place in digitally driven spaces have moved onto internet platforms. Any service or business that can be digital and deliver digitally will stay digital. Lots of organisations will want to capture and keep the advantages that home-based activities have brought. Advantages like not having to transport people from place to place and the broadening of ways of delivering services, information and resources on-line. Of course this will mean that those learning-disabled people who cannot or choose not to do things online will be very disadvantaged.

Digitisation of public services/adult social care:

Follow on from the effects of the pandemic, service-providers and businesses will move as many services as they can online. With this, tele-care, voice-activation and technology that supports care at home will be deployed more and more as well. We will see more remote staff supporting the person at home. The pandemic has in many ways just accelerated this trend of more digitalised and technology-driven services provision. This trend will persist.

Digital inclusion

Estimates vary as to the extent of digital inclusion and exclusion in the UK. It is suggested that 9 million people 'struggle to use the internet without help'²⁴. Availability is less of an issue as 96% of UK households have internet access²⁵. Learning-disabled adults are less likely to have access to all the benefits of digital information and digitally-driven spaces. However these generalisations mask some other factors. Some learning-disabled adults will prefer on-line spaces. They can have more control and freedom over who they socialise with and communicate with and can have more anonymity. So therefore, there are some instances where digitally accessed spaces can increase social inclusion. For instance, a learning-disabled person might attend an arts class, social group or health and well-being

²³ Mencap. *Employment – what we think*. 2020. Accessed January 12th 2021. [Employment - what we think | Mencap](#)

²⁴ Good Things Foundation. *We believe in a world where everyone benefits from digital*. Accessed January 17th 2020 [Digital Health Lab \(digital-health-lab.org\)](#)

²⁵ ONS (Office for national Statistics). *Internet access – households and individuals* Accessed January 15th 2021 [Internet access - households and individuals - Office for National Statistics \(ons.gov.uk\)](#)

activity online that they would not attend in person. Age is a factor also. 'Digital natives' was the term coined for people who have grown up in the digital age. Younger people only know a world substantially organised through digital devices and spaces.

As more and more of life will be online - during covid and post-covid - it is important that ever that PWLD are digitally included wherever this is possible, and that specific measures and resources are devoted to digital inclusion activities especially amongst public services such as health and social care.

Digital issues and access to services

The Covid19 pandemic has accelerated a hidden need. It is so often the case that needs and problems can be hidden or obscured until they present themselves further down the time-line. For instance, poor access to health care due to exclusion from technology can have severe repercussions if disease is not being picked up at the right time. The pandemic has resulted in delays to Annual Health Checks for learning-disabled patients as well as in-person appointments being removed²⁶. Also the NHS is looking to reduce in-person appointment in out-patients by a third - a target that has been greatly accelerated by lockdowns and the NHS responses to them.

Equalities legislation:

In general in society we see people claiming their rights and using equalities legislation to do this. Service providers and employers have duties under the Equalities Act 2010 not to discriminate against people with 'protected characteristics'. The nine protected characteristics includes disabilities:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation

We might see disability organisations push services harder to make better 'reasonable adjustments' in order to improve public or business services for disabled/learning disabled people in general

Parents:

As many 'equalities groups' have claimed rights to certain thing so too have learning-disabled people claimed their rights to many things including parenting. However parents

²⁶ Mencap, *My health My Life* (2020) Accessed February 1st 2021 [MyHealthMyLife_COVID report.pdf](#)

with learning disabilities are far more likely to have their children subject to care proceedings. This is a complex area. The main point for this report is that the boundaries of 'safe and secure parenting' will continue to be pushed and tested. With this comes potentially demands for intensive, high-quality advocacy support, as well as a need for early stage advice and information to help learning-disabled people who consider having a child. Services are not well resourced or well prepared to deal with the needs in the areas of potential parenting and parenting itself. As there will be, most likely, more cases of learning-disabled adults wishing to become parents this is an area of important unmet.

Cuts to adult social care funding and austerity

Since 2010 social care services have been reduced, benefits have been cut and access to care and support has been made more difficult. One of the results of this has been less social participation and more loneliness and isolation amongst learning-disabled people. Over this ten-year period some 're-shaping' of services has occurred, but not always for the best of reasons. A study featured in the Disability in Society journal states that:

'It has been suggested that governments conceal some retrenchment strategies behind this vision of creating a society in which disabled people are 'empowered' to gain independence'²⁷

Adult social care remains mostly funded through local authorities and we see no signs that finances are getting any better. Brighton and Hove is looking to cut £13 to £15 million in 2021/2022 and social care is its largest budget. It is being recommended that £950,000 is to be cut from the learning-disability budget in Brighton and Hove. With councils like Croydon and Northampton going bankrupt, non-statutory services – like parks, some transport, and most grants to third-sector organisations – will remain vulnerable to cuts. This means that direct and indirect support services and activities for the learning-disabled are highly vulnerable to cuts.

NHS based funding will not be as fiscally tight though the demands on its services will be huge. This means that Speak Out needs to continue to try and appeal to the funding preferences and interests of the CCG as well as to other commissioners and funders.

Unfortunately the levels of care support for PWLD continues to look bleak unless the government makes big changes to social care policy and financing.

New models of care and support:

Despite some elements of the public funding picture looking bleak, Brighton and Hove and the UK has a thriving voluntary and community sector. With this come lots of innovations

²⁷ Malli M.A. et al, . *Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature* 2018. Disability and Society journal. Accessed January 17th 2021.
<https://core.ac.uk/download/pdf/189721603.pdf>

and development in ways of supporting people. 'Shared lives' type housing and 'social prescribing' for NHS patients are two examples in recent years. Any innovation that is low cost and or 'light-touch' will win favour as regards funding also. Speak Out needs to gauge how its current activities, and possible future activities, fit with current thinking amongst commissioners and funders. Speak Out needs to evaluate current and future work possibilities against current service and support models and policies and commissioning preferences and trends, as well as taking into account needs and preferences of people with learning disabilities.

14. Conclusion

Speak Out addresses many different needs and helps people to solve or make progress with lots of problems. The many ways Speak Out provides advocacy and support to PWLD means that many issues that affect PWLD are being tackled. Speak Out meets lots of needs skilfully and with a variety of ways for people to engage, be helped and help others. Advocacy is helping people with everything from housing, relationships and benefits through to transitions, finance/benefits, adaptivity to the conditions of the pandemic and more. Purely from the meeting of needs point of view Speak out is doing very well. This said there are choices to be made about *what* issues need to be addressed, and *how* Speak out can address them.

APPENDIX ONE – use of Speak Out’s covid-19 helpline

Speak Out helpline only, 9-month figures*:

SUMMARY:

Support around anxiety	179	17%
Support around isolation	648	62%
Mental health and well being	84	8%
Other issues (health, benefits, other)	48	5%
Other corona-virus related	81	8%
Cases total	1040	

DETAILED CLIENT STATISTICS:

	Q2	Q3	Q4	Total	
Safeguarding	1	0	4	5	5
Family/relationships/social networks	4	1	1	6	6
Finance/benefits	1	7	3	11	11
Housing/accommodation:	6	3	3	12	12
Complaints:	1	0	0	1	1
Social care:	2	2	0	4	4
Health:	9	0	0	9	9
Mental Health and Well Being:					
Accessing Mental Health Services	3	1	0	4	4
Access to services	1	8	23	32	32
Quality	35	12	1	48	48
	39	21	24	84	84
Corona Virus:					
General	9	0	0	9	9
Support to follow guidelines	18	1	0	19	19
Support to understand health info	6	0	2	8	8
Access to support	28	3	1	32	32
Access to food	9	0	0	9	9
Access to medical help	4	0	0	4	4
Support around anxiety	90	48	41	179	179
Support around isolation	390	169	89	648	648
Total	554	221	133	908	908
					104
Grand total	617	255	168	1040	0

APPENDIX TWO – Building blocks for self-building daily lives



Fig. 1 Building blocks for self-building daily lives

Underpinning the building blocks, we identify three enabling factors to promote successful self-building:

1. Advocacy, including self-advocacy: Supporting this is essential, especially for the most isolated, to provide people with the skills and confidence to make their voices heard. This is a crucial step to enable people to take part in their communities.

2. Member-led involvement¹: Involving members with learning disabilities in management and advisory roles (for example, on steering groups) can ensure support organisations create something people want and have a commitment to, and where they can learn together.

3. Social interaction: Facilitating opportunities for people to make and meet friends is necessary as day-centre use declines. Friendship groups and networks can foster peer-support, and help participants gain the skills and confidence to live as part of their wider communities.

These enabling factors need to be promoted and supported by policy makers, local authorities, support organisations, national learning disability and related organisations.

Finally, we outline a series of recommendations in the following pages.

¹ We refer to member-led rather than user-led to indicate that people with learning disabilities are increasingly taking active roles in support organisations rather than being passive users.