

# Consultation Response: Inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales

Evidence to: Health, Social Care and Sport Committee, Senedd Cymru

Joint response from: All Wales People First, All Wales Forum of Parents and Carers, Learning Disability Wales, Downs Syndrome Association, Mencap Cymru, Cymorth Cymru. Submitted on the 26.06.2020

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## About the submitting organisations

### All Wales People First (AWPF)

All Wales People First is the united voice of self-advocacy groups and people with learning disabilities in Wales. All Wales People First is an organisation for, and led by, men and women with a learning disability. It is unique in Wales in that it is the only national member-led organisation that represents the voice of men and women with a learning disability.

### All Wales Forum of Parents and Carers (AWF)

The All Wales Forum's mission is to bring a national voice and recognition to parents and carers of children and adults living with learning disabilities in Wales. AWF is unique among learning disability organisations in that it is the only organisation that represents solely the views of parents and carers of people with learning disabilities across Wales.

### Learning Disability Wales (LDW/E2C)

Learning Disability Wales (LDW) is a national charity representing the learning disability sector in Wales. Everything that we do focuses on creating a Wales that values and includes every child, young person and adult with a learning disability. We do this through working with people with a learning disability and their families, Welsh Government, local authorities, disabled people's organisations and the voluntary sector. Incorporating the Engage to Change Project (E2C). Project partners of Engage to Change are Learning Disability Wales, All Wales People First, Agoriad Cyf, ELITE Supported Employment Agency and the National Centre for Mental Health at Cardiff University.

### Downs Syndrome Association (DSA)

The Downs Syndrome Association (DSA) is the only charity in the UK dealing with all aspects of Down's syndrome. Its aim is to help people who have Down's syndrome live full and rewarding lives.

### Mencap Cymru (Mencap)

Mencap Cymru is the voice of learning disability in Wales. Our vision is a world where people with a learning disability are valued equally, listened to and included. Mencap runs different services and projects for people with a learning disability including the Wales Learning Disability Helpline.

### Cymorth Cymru (CC)

Cymorth Cymru is the representative body for providers of homelessness, housing and support services in Wales. We act as the voice of the sector, influencing the development and implementation of policy, legislation and practice that affects our members and the people they support. We are committed to working with people who use services, our members and partners to affect change. We believe that together, we can have a greater impact on people's lives.

## Executive Summary

We are submitting this response on behalf of people with a learning disability, their families and carers. We draw from reports conducted by several of our member organisations consisting of people with a learning disability themselves, People First Groups across Wales, family carers and service providers.

Our findings are:

- People with a learning disability and their families are struggling with significant anxiety and confusion. People are worried about coronavirus itself, the ambiguity of lockdown rules, and worries about the future.
- Many people have reported difficulties regarding the process of shielding. Sometimes people who should have been shielding have not received shielding letters, at other times people received them without understanding why.
- Staying safe has been a challenge for many people with a learning disability. People have reported several problems with accessing food and other commodities. They are worried about the safety of their paid support and struggle to access appropriate PPE.
- People with a learning disability have been struggling to access non-Covid-19 related health care. They have been missing out on Annual Health Checks and many have found interacting with their GP over the phone challenging.
- People with a learning disability are struggling with having lost significant support, in particular services, social workers and respite care. We are concerned not only about the effect that this loss of support has on people right now but also of the long-term effects. Parents with learning disabilities in particular are worried about losing custody of their children after the end of lockdown because they are not getting the support they need with their children right now.
- The impact on people with a learning disability who were employed pre-Covid-19 varies quite significantly and those who continue to work have had to learn new things about the new ways of working and what they need to do to keep themselves safe while travelling to/from work and while at the workplace.
- There are some small positives being reported. Some people with a learning disability are learning new skills and we have reports of great community support. We have also found Welsh Government largely responsive to our concerns throughout this crisis.

## Background

In 2018 to 2019 there were 13,507 people with a learning disability known to social services in Wales. Of these 11,001 lived in the community, 1424 were living in their own home, 7065 were living with parents/family, 2283 were living in supported living and 229 in foster care. Of the remaining people with a learning disability 108 were living in health services (including hospitals/hostels), 94 were living in local authority residential accommodation and 1206 were living in private or voluntary residential accommodation. 518 were living in other accommodation<sup>1</sup>.

The number of people with a learning disability in Wales known to social services has decreased in comparison to the previous years. This is likely due to the fact that learning disability diagnoses have become harder to come by. Taken together with other cuts made due to austerity measures, many people with a learning disability in Wales will have already had difficulty accessing the support they need before Covid-19, leaving them particularly vulnerable to the effects of both Coronavirus and the lockdown.

We know that even before Covid-19 people with a learning disability were subject to serious health inequalities. A recent report from Welsh Government found that

*“wide-ranging evidence to suggest that disabled people in Wales experience considerable general and more specific healthcare access issues. Background evidence suggests there is a strong correlation between poverty and disability and that such poverty is compounding already existing inequalities in access to better health. For example, many disabled people have considerably shorter life-expectancies and there is evidence to suggest that this is caused by inequitable levels of healthcare provision<sup>2</sup>.”*

These existing health inequalities will have likely worsened both the vulnerability of people with a learning disability to Covid-19 and also made the loss of other support due to lockdown and the strain on the health service more dramatic.

## How we created this report

All contributing organisations have engaged with people with a learning disability, carers of children and adults with a learning disability, and service providers. Several of the contributing organisations have published documents independently and these are listed in a bibliography at the end. After

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<sup>1</sup> Statswales 2020: <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Disability-Registers/personswithlearningdisabilities-by-localauthority-service-agerange>

<sup>2</sup> <https://gov.wales/review-evidence-inequalities-access-health-services-wales-disabled-people>

some of the items in the report we have put the name of the organisation in whose report the specific point is best illustrated.

## Findings

### Confusion and anxiety

- Most people with a learning disability reported feelings of loneliness, isolation, boredom and frustration due to the cancellation of meetings and events, such as local People First Groups (AWPF). This loneliness is particularly worrisome since people with a learning disability struggled with loneliness pre-Covid-19. In a 2019 survey Mencap found that 24% of people with a learning disability reported feeling lonely “a lot.”<sup>3</sup>
- Generally people with a learning disability living on their own struggle more with loneliness than those living with others. However, people living with others reported similar experiences of social isolation to those living alone (AWPF).
- Confusion about what exactly is going on and what the future holds is a major concern for people with a learning disability. Those with mental health issues and/or neurological conditions are struggling to remember the reasoning behind the sudden changes and a small minority are exhibiting some extreme behaviour including suicidal thoughts. Where required, support workers are calling in other organisations and agencies to help those most vulnerable and in need of urgent support. The lack of an end date or defined timescale is causing confusion and anxiety, as are the multiple news updates from a variety of sources, most of which are difficult to understand. A further issue is that it is not always clear whether or not the rules from the UK Government also apply in Wales or how the rules might be different. This is not helped by the UK media regularly reporting English news as though it applies to the UK as a whole (AWPF, LDW).
- People are aware of the risk of mortality from coronavirus. This is causing anxiety for people’s own lives and also how they will cope with losing somebody they know
- Some children and young people with a learning disability also have underlying health conditions and there are now significant levels of anxiety amongst their families about whether it will be safe for them to return to school or college when these settings begin to reopen. Some individuals are therefore facing an extremely long period of being isolated at home and missing out on education (DSA, LDW).
- There has been confusion around the exercise rules. For example, some people with autism thought the rules were stating that they could not go outside without a carer or other person (LDW, AWF).

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<sup>3</sup> Mencap, 3 December 2019, People with a learning disability seven times as likely to be lonely this Christmas, <https://www.mencap.org.uk/press-release/people-learning-disability-seven-times-likely-be-lonely-christmas>

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- People are confused around the term “social” distancing and it has been suggested that physical distancing would be more appropriate and more accessible (AWPF).
- Some people have voiced concerns over emergency powers and local authorities using them during this crisis. In England, the guidance on measures to reduce pressure on services states that councils still need to adhere to the Human Rights Act but in Wales it is a judgement call (Mencap).
- We have heard concerns from autistic people and from carers of disabled children in South Wales that the ambiguity of lockdown rules is causing significant anxiety. This anxiety has been amplified by worries about what one autistic person we talked to called “vigilantism”. Autistic people, in particular, are worried about being harassed by members of the public or indeed by members of the police force on the grounds of social distancing rules. The reason these rules are so hard to follow is that they are often contradictory and confusing. In addition, people describe struggling with unwritten rules. For example, one person described being harassed in a supermarket for looking at produce too long (LDW).

### Difficulties relating to shielding

- Statutory letters offering help, advice and instructions from local services and the Welsh Government are slow to arrive and when they do, there is no support available to help with reading and understanding the content. There is currently no easy read version of the shielding letter available. Mencap asked Welsh government for an addition to the shielding letter advising people to call the Wales Learning Disability Helpline if they had difficulty understanding the letter. (Mencap).
- Some people with a learning disability have received shielding letters, even though it is not clear to them or their family why they should be shielding. Whilst there does not appear to be a widespread issue of people not following the guidelines, a lack of understanding of the letter has led to some people going out when they should be shielding. There are also some individuals who do not understand that, because they live in the same house as someone else who is shielding, they must also shield in order to protect that person (Mencap, LDW).
- Some people with a learning disability and other health conditions feel that they should have received a shielding letter from their doctor and are confused why they have not. They are worried about the best way to stay safe knowing that they have a health condition, yet have not been advised to shield (AWPF).
- Some people with a learning disability have not received a letter from their GP advising them to shield, yet they have been told to shield by care staff and/or their housing provider. In the absence of clear communication, they are confused about the rationale behind the request to shield. They have either expressed concerns that they may have a health issue which has not been communicated to them, or expressed frustration as to why the rules about shielding are being imposed on them (AWPF).

### Staying safe and healthy

- Some people with a learning disability, especially people with Down Syndrome, have underlying health conditions which means they often chose to self-isolate before it became obligatory (DSA).
- People have reported several problems with accessing food and other commodities. Priority shopping times are often too early and the queues are too long for some people. Some have asked for: personalised/appointed time slots (eg in the evening or at a specific preferred time); a priority shopping delivery system (although with concern over increased risk of contamination from delivery service); and a list of people who might get preference (Mencap).
- People with a learning disability have also reported multiple other issues around shopping: fears about having to use public transport to get there; the one-way system in stores being hard to navigate; on-line shopping not being accessible; a lack of support to get shopping done in alternative ways to going in person<sup>4</sup>.
- People are worried about the safety of paid support. Parents of people with a learning disability are doing risk assessments and taking measures at their own discretion. They also struggle with a lack of PPE and there is some confusion around whether the Direct Payment scheme will cover the cost of PPE. There is further confusion around Direct Payments and suspended services (eg carers continuing to be being paid etc. There is a wide disparity in the advice given by Direct Payments leads in local authorities (Mencap).
- Letters for keyworkers are difficult to obtain for people (Mencap).
- People with a learning disability have been struggling to access non-Covid-19 related health care. Specialists have not been visiting private homes or supported living facilities. Basic care needs have not been met (eg toenails not being cut). There are no annual optician or dentist reviews taking place and only emergency dental procedures with a very strict list through hospitals can be accessed (Mencap). This is particularly worrying given that adults with a learning disability are up to 10 times more likely to have serious sight problems than the general population.<sup>5</sup>
- All GP appointments are either over the phone or virtual, which is challenging for some people, especially those with communication difficulties.

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<sup>4</sup> Some of these issues are illustrated in the All Wales People First Member's Story of Anne and Neil, <https://allwalespeople1st.co.uk/members-stories-life-in-lockdown-3/>

<sup>5</sup> SeeAbility, 2016, Delivering an equal right to sight <https://www.seeability.org/Handlers/Download.ashx?IDMF=316cd01e-01c4-452c-8951-b16a87a0674f>

- There is concern that Annual Health Checks will have been paused and may take some time to resume, meaning there will be a backlog. Knowing the health inequalities that individuals with a learning disability often experience, this area of NHS activity should be prioritised (DSA). Annual Health Checks are an important tool in the early identification of health issues and managing long-term health conditions in order to reduce the high numbers of premature deaths among people with a learning disability. A study funded by the Department of Health in 2013 found that on average women with a learning disability die 20 years younger than those in the general population and men with a learning disability die 13 years younger than those without a learning disability.<sup>6</sup>
- People also have difficulty accessing medication. Complicated procedures to change medication through email are not accessible for everyone and neither are webchat methods on websites to get a prescription. There are often long queues for medication or difficulties in getting deliveries for those who have not already set this up prior to the pandemic.

### Loss of support

- People with a learning disability are struggling with having lost significant support. They now have to spend extensive periods of time without day service activities, have had activities substituted with virtual activity plans and have extensive periods of time without any respite services. There needs to be increased support for unpaid carers looking after adults with a learning disability as it can be challenging to care for an adult 24 hours a day without any form of respite (Mencap, AWF, AWPf).
- In areas where they rely on volunteer groups and community support, people have voiced concerns over possible coronavirus contamination (Mencap).
- Parents are not being allowed to visit their sons and daughters in care homes/supported living. Having no plans in place for when the next visit will be is causing distress to both parents and sons/daughters. Similarly, parents of people with a learning disability who live far away from their adult children do not know when they will be able to see them next.
- The status of some young people's college placements is now uncertain. The 2020 academic year effectively ended in March rather than July. Where college placements are residential, it could be that some young people will miss out on one third of a year of the placement they were expecting (DSA).
- We are also concerned about the possible impact on people with a learning disability and their families/carers of the emergency 'backlog clause' that allows local authorities time to catch up on services after the peak of the crisis has passed. This could mean that people

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<sup>6</sup> Bristol University, 2013, Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) <https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>



continue to be left without services for an unknown length of time after the lockdown has finished (Mencap).

- There are significant concerns around how parents with a learning disability are managing without support. One parent with learning disability reported that they are not receiving support or contact from their social worker. There are fears of unfair assessments for parents with a learning disability after the lockdown, especially given that it might take time for services to offer support again. Welsh Government needs a policy that clarifies how parenting assessments will be carried out after the crisis. This is to ensure the protection of the rights of parents from unfair assessments or removal of parental rights. There are still many questions unanswered around the situation of parents with a learning disability. What is happening in terms of family court? Are parents being asked to wait before finding out if their child is to be removed permanently? What discussions are taking place with the Courts and Tribunal Service? (Mencap).
- Poverty remains a great concern for many people with a learning disability. People have reported delayed assessments that affect their benefit payments. This has led to at least one person having to use a food bank and emergency support offered through their church (LDW).
- Welsh Government needs to implement wellbeing checks through local authorities to make sure people with learning disabilities can access the support they need).

## Employment

- The impact on people with a learning disability who were employed pre-Covid-19 varies quite significantly. Some people continue to be employed in key worker roles, with others becoming newly employed during this time. Some people in key worker roles have withdrawn themselves, been laid off or furloughed. There are people with a learning disability who are now home working if they have a job role and employer that enables this (AWPF, E2C).
- There is an ethical question that has to be asked as to what understanding those who continue to work have of the new ways of working and what they need to do to keep themselves safe while travelling to/from work and while at the workplace. In some cases, if supported by an employment project, they have been provided with additional training and support to help with this. However, there are instances where information has been sent to employees by their manager that is not in a format they can understand (E2C).
- Reasons for no longer being at work or employed vary. There are those whose health conditions or the health of others in their household means they are isolating or shielding. Some people have withdrawn themselves from the workplace due to their anxieties and fears and/or the concerns of their parent/carers. Employers whose business is currently closed have either laid off or furloughed all of their staff. This can be hard to understand and will have an impact on household income including benefits (E2C).

- People with a learning disability and their parents/carers need support to understand what being furloughed or laid off means in real terms. Also to understand their employment rights and to apply for benefits in light of either a reduced salary or no salary at all (E2C).
- Anxiety levels are high with mental health, well-being and mindfulness support being much needed. Going to work provided a structured day and in many cases a social and supportive environment that contributed to feelings of self-worth and built confidence (E2C).
- We are concerned that people with a learning disability who are now short term unemployed will become long term unemployed as lockdown gradually reduces. Many people will become de-skilled and have to relearn tasks and/or learn new tasks. Some people will have to have a complete change in direction as employment opportunities and work environments are likely to change. As a nation we do not do well when it comes to the percentage of people with a learning disability in paid employment. Economic forecasts suggest unemployment will be high in the general population post-Covid-19, especially for people aged 18-30. This will likely have a significant impact on the employment of people with a learning disability. It will be harder for those who have become unemployed and those yet to gain employment to get a paid job. Younger people with a moderate learning disability might be particularly at risk as they may not be eligible for day services and have very different aspirations. There is a real fear that a new cohort of disconnected young people with moderate learning disabilities will be unknown to services and at risk of criminalisation<sup>7</sup> (E2C, Mencap).

### Positive reports

- There are some small positives being reported. Some people with learning disabilities are gaining new skills and confidence in using social media, communication tools and other apps. Local communities are also rallying around to help vulnerable people and it is hoped this will lead to more positive and proactive relationships in the future. Those living with others are also forming stronger bonds and working more closely with each other. In some shared accommodation, residents are supporting each other by cooking meals for everybody and/or sharing tasks between them. However, some are reporting conflict and tension from too much time in each other's company (AWPF).
- There are a number of people with a learning disability who have gained employment during this time, some as a direct result of Covid-19. In addition, some people who had been furloughed but have now been supported to return to work (E2C).

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<sup>7</sup> For an extensive review of the literature on learning disability and learning difficulty and criminalisation in England and Wales please see Nancy Loukes (2007): No one knows, offenders with learning difficulties and learning disabilities – review of prevalence and associated need. Available online:

<http://www.ohrn.nhs.uk/resource/policy/NoOneKnowPrevalence.pdf>

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- Other positives include ongoing support being provided remotely for people participating in a supported employment programme. For example, to develop work skills, complete accredited courses, seek employment, apply for benefits, improve mental health and wellbeing (E2C).
- Welsh Government officials throughout the coronavirus crisis have been open to working and meeting weekly with third sector partners as part of the Learning Disability Ministerial Advisory Group (LDMAG) to discuss current themes/issues. Jane Hutt and Julie Morgan meet members of the Disability Advisory Forum fortnightly. This is unique and does not happen in other UK countries and gives real-time access to civil servants and Ministers to raise issues directly from people with a learning disability and their parents/carers (Mencap).

## Other important resources

### Previous joint statements:

Coronavirus (COVID-19) and the rights of disabled people in Wales - [Statement from the members of the Wales Disability Reference Group](#), 08.04.2020

[Disability Wales](#), [Learning Disability Wales](#), [Wales Council of the Blind](#) and [Wales Council for Deaf People](#), <https://www.ldw.org.uk/coronavirus-covid-19-and-the-rights-of-disabled-people-in-wales/>

NICE guidelines still cause for concern for disabled people, 27.03.2020

[Learning Disability Wales](#), [All Wales People First](#), [All Wales Forum](#) and [Mencap Cymru](#), <https://www.ldw.org.uk/nice-guidelines-still-cause-for-concern-for-disabled-people/>

Coronavirus Bill: Suspension of Social Services and Well-being Wales Act (2014), Welsh National Disability Umbrella Organisations, 24.03.2020

<https://www.ldw.org.uk/corona-virus-bill-suspension-of-social-services-and-well-being-wales-act-2014/>

Joint response to Coronavirus outbreak across Wales, 19.03.2020

[Disability Wales](#), [All Wales People First](#), [Wales Council of the Blind](#), [All Wales Parents and Carers Forum](#), [Learning Disability Wales](#) and [Mencap Cymru](#), <https://www.ldw.org.uk/joint-response-to-coronavirus-outbreak-across-wales/>

### All Wales People First

The effect of the coronavirus pandemic on people with learning disabilities, 12.05.2020

Available online at: <https://allwalespeople1st.co.uk/effect-of-the-coronavirus-pandemic-on-people-with-learning-disabilities/>

All Wales People First has also collected a number of **Members Stories** that give a detailed view of the lives of people with a learning disability. They can be found here: <https://allwalespeople1st.co.uk>

## Contact

For more information on this report and the issues raised in please contact

Policy Officer – Learning Disability Wales