

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

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Anabledd Dysgu Cymru/ Learning Disability Wales



Supporting people with chronic conditions

Evidence committed to the Health, Social Care and Sports Committee

Deadline 25.05.2023

Response on behalf of Learning Disability Wales

Learning Disability Wales is a national charity representing the learning disability sector in Wales. We work with people with a learning disability and their families, Welsh Government, local authorities, disabled people’s organisations and the voluntary sector to create a better Wales for all people with a learning disability.

Contact

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Editorial note

Note: We are not completely sure here on your definition of “chronic condition” and how it relates to the concept of disability. For the purpose of this response, we will not consider having a learning disability itself as a chronic condition. Instead, we will give evidence in regard to the experience that people with a learning disability have in terms getting support when they have other long-term conditions that they need support with.

We can give evidence on a few different issues in terms of the difficulties people with a learning disability can have getting good support with health conditions.

We have structured our response along the areas of enquiry you have asked for in the call for evidence to this consultation. In detail we have given evidence of the following topics:

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1. NHS and social care services

Annual health checks and health check champions

The importance of annual health checks has been emphasised by the 2021 NICE guidelines¹ on people with a learning disability and by Improvement Cymru in 2022². Annual Health Checks are a major facilitator to help people with a learning disability get diagnosed with long term health conditions and access treatment. Several research studies over the last 15 years have also evidenced the positive impact of annual health checks for people with a learning disability. Most recently, a study by researchers from Swansea and Cardiff Universities in 2022 showed that having a health check was associated with reduced deaths, particularly for autistic people and those with Down's syndrome³.

Despite this, both uptake and provision of annual health checks has been patchy to say the least across Wales with uptake in many areas still worryingly low. In the Cross Party Group on Learning Disability in September 2022 we urged Welsh Government to address this issue as a matter of urgency.

We believe that Health Check Champions are a good way to encourage people with a learning disability to attend their health checks and tackle health inequalities in Wales. You can find out more about the Health Check Champions from Conwy Connect on their website here: <https://www.conwy-connect.org.uk/health-check-champions>. We believe that all health board areas in Wales should consider employing people with a learning disability to promote annual health checks within their communities. This will help to

¹ 1 NICE. [2021], Impact Report: People with a learning disability. Available here: <https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/nice-impact-people-with-a-learning-disability>

² 2 Paula Phillips [2022], The importance of Annual Health Checks (AHC) for people with a learning disability. Available here: https://www.improvementcymru.net/en/2022/05/25/annual-health-checks/#_ftn1

³ 3 Natasha Kennedy, Jonathan Kennedy, Mike Kerr, Sam Dredge, Sinead Brophy [2022], Health checks for adults with intellectual disability and association with survival rates: a linked electronic records matched cohort study in Wales, UK. Available here <https://bmjopen.bmj.com/content/12/4/e049441>

improve uptake and also help people to feel more prepared for their annual health checks so that they can get the most out of them. This has the potential to lead to a reduction in health inequalities and ultimately contribute to reducing the high levels of premature deaths among people with a learning disability in Wales.

Reducing restrictive practices

People with a learning disability and autistic people often face restrictive practices, especially within mental health settings. When it comes to seeking treatment for mental health conditions or other forms of distress it is important to note that doing this may put people with a learning disability and autistic people in danger of having their fundamental human rights violated. It is important to note that at a time when they are in the greatest distress, mental health facilities are often not safe spaces for them and that mental health issues can be escalated and made worse through the treatment that people with a learning disability and autistic people sometimes experience in these settings. In order to make sure people with a learning disability can get the mental health support they need, the Reducing Restrictive Practices Framework⁴ must be fully implemented. In particular, it is important that behaviours that people may have because they are distressed or struggling with mental illness is not reacted to in a punishing way that can lead to increased distress.

Digital exclusion – general easy communication

It is important to remember that many people in Wales are still digitally excluded for a variety of reasons including lack of access to the internet and/or suitable devices, and lack of knowledge/skills. People with a learning disability are more likely to be digitally excluded due to added issues around perceived safeguarding risks and a lack of accessible training and support to get online safely. In terms of accessing health care and getting support with long term health conditions, digital exclusion may stop people from getting access to health care or appointments. We have heard from people with a learning disability who have struggled to get GP appointments or vital information because they have not been able to navigate online systems. It is important that for every service there are options available that do not require patients to have smart phone access or digital skills.

Medical trauma

Whenever engaging with people with a learning disability around health systems it is important to acknowledge the depth to which many (if not most) people with a learning disability experience medical trauma. We are

⁴ Welsh Government [2022], Reducing Restrictive Practices Framework, Available online <https://gov.wales/reducing-restrictive-practices-framework>

currently awaiting publication of a report we produced⁵, commissioned by Public Health Wales, about people with a learning disability and vaccines. In the focus groups conducted for this report, people with a learning disability reported being treated badly (or “roughly” as some of them put it) in many medical appointments. People reported feeling they were not being respected by medical professionals and that they were often not given the time to process the information they were given. Another finding from the focus groups and interviews was that our participants were overwhelmingly terrified of needles as well as what others might perceive as “mild” side effects.

What these two findings tell us is that any approach to delivering health care to people with a learning disability has to be informed by an understanding of trauma and the way it affects people. The fact that people with a learning disability will have likely had bad experiences in the past and have significant fear because of that needs to inform future work and engagement.

Lack of learning disability awareness in specialist services

Having a long term condition often means having to engage with specialist services. We are concerned that there may be inadequate learning disability awareness training within specialist services. It is important that people with a learning disability can get reasonable adjustments with specialist settings as well as in general.

2. Multiple conditions

Health inequalities

People with a learning disability experience significant health inequalities compared to the rest of the population with 41% of adult deaths being due to treatable medical causes and 21% being due to preventable medical causes.⁶

While we do not have specific evidence of wider mental health inequalities for people with a learning disability in Wales, we have strong reasons to believe that people with a learning disability struggle more with their mental health and struggle more with getting appropriate support than other people. We do not have specific data for Wales but a UK-wide study in 2007⁷ found that 52% of people with a learning disability had mental health issues. Scottish census data from 2011 indicates that mental health conditions were

⁵ This report will be publicly available on or after 12 June 2023. If you would like to receive a copy of the report, please email Grace at [REDACTED]

⁶ NICE. [2021], Impact Report: People with a learning disability. Available here: [NICE impact people with a learning disability](#)

⁷ Cooper, S.A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. *The British Journal of Psychiatry*, 190, 27–35.

reported for 21.7% of people with learning disabilities compared to 4.3% of other people⁸. We would like to draw the Committee's attention to work done by Mencap UK⁹ and Public Health England¹⁰ outlining some of the reasons why people with a learning disability are more likely to struggle with their mental health than other people.

Symptoms may appear differently

People with a learning disability and neurodivergent people may have different ways of experiencing their bodies as well as expressing their emotions. This means that they may express fear or pain in very different ways than what medical professionals may be expecting. They may not be able to express their symptoms in the way that people usually do. Even when they do, health professionals may not believe them because their demeanour might be different from the way that people usually act. Any attempt to improve health care outcomes for people with a learning disability has to include training that makes medical professionals aware of these differences and how symptoms may appear differently for disabled people. This point has also been made by Welsh Youth Parliament member Tegan Skyrme who has been campaigning for disabled people to get better mental health support.¹¹

Diagnostic overshadowing

Diagnostic overshadowing: For many people with a learning disability, as well as for many neurodivergent people, diagnostic overshadowing can pose a real issue in accessing mental health support. Mental health professionals may not understand the difference between behaviours and feelings that have to do with the learning disability or neurodivergence and those resulting from distress or mental illness. This lack of understanding means that people will often not get appropriate mental health support. Mental health professionals need better training and education in how mental health difficulties may present in and affect people with learning disabilities and neurodivergent people.

Often it can be hard for disabled people, for example neurodivergent people and people with learning disabilities, to get good support with mental health issues. Diagnostic criteria are often developed based on what

⁸ 2 Hughes-McCormack LA and others. Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population. *BJPsych Open*, 2018

⁹ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/mental-health>

¹⁰

https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKewjNgJbTgpT2AhURO8AKHRThCF8QFnoECAQQA&url=https%3A%2F%2Ffingertips.phe.org.uk%2Fdocuments%2FHealth%2520Inequalities_Mental%2520health%2520problems.pdf&usg=AOvVaw3ncUEefxGCMbkZmkAoTt5s

¹¹ Disabled people need better mental health support, Learning Disability Wales Blog, <https://www.ldw.org.uk/disabled-people-need-better-mental-health-support/>

symptoms look like in specific groups (most often white, cis-gender, neurotypical men). It is important for people working in specialist services to be aware of how conditions may manifest differently and need different treatment in other groups. While it would be good to have all mental health professionals be trained in understanding intersectional issues and comorbidities, it would also be good to make sure highly specialised staff are available in at least one place in Wales.

While we have emphasised mental health services here, it is worth pointing out that these issues will also be relevant in other areas. For example, autistic people will often have different pain perceptions than neurotypical people, making it harder to diagnose some physical conditions. It is therefore important that within specialised health services, there are enough staff trained in understanding neurodiversity and other disability related issues.

3. Impact of additional factors

Impact of the pandemic

We know that throughout the pandemic disabled people have been disproportionately affected by lockdown measures and loss of support systems. This affects their way to get support with health conditions. As the Locked Out Report¹² highlights, disabled people have experienced very significant limitations in their access to all kinds of health care. Drawing on data from the ONS, the Locked Out report writes that “Almost half (47%) of disabled people [in September 2020] reported high anxiety compared with less than a third (29%) of non-disabled people. Furthermore, disabled people reported more frequently than non-disabled people that the pandemic is affecting their well-being because it makes their mental health worse (41% for disabled people and 20% for non-disabled people); they feel lonely (45% and 32%); they spend too much time alone (40% and 29 [...]) Factors such as isolation, loneliness, restrictions on movement, withdrawal of established social and statutory support, inaccessible services and public spaces, poor socio-economic living conditions, confusing public messaging, etc. played significant contributory roles. High levels of ‘worry’ and anxiety were reported among disabled people (ONS)”.

Similarly, a study about the experience of people with a learning disability in Wales found that people with a learning disability experienced very significant challenges to their wellbeing during the pandemic. In January 2021, 84% of the people in the study reported being sad or worried most or all of the time. The level of distress experienced by people with a learning disability will have long term consequences in terms of their mental health going forward.

¹² <https://gov.wales/locked-out-liberating-disabled-peoples-lives-and-rights-wales-beyond-covid-19-html>

The Locked Out report also found that disabled people experienced significant difficulties accessing health services during the pandemic. Worryingly, we have heard evidence from people with a learning disability that support levels and provision of services have not returned to pre-pandemic levels for many people.

Economic disadvantage and cost of living

Another thing to take into consideration when it comes to why people with a learning disability have worse health outcomes is that people with a learning disability tend to be poorer than other people in Wales.

A study conducted by the Joseph Roundtree Foundation¹³ into the finances of families of disabled children in 2018 found that only 18% of respondents said that their disability benefits could cover the extra costs linked to their child's disability or health condition. These extra costs are significant, with 33% paying over £300 a month and 10% paying between £500-£1000 a month in disability related costs. 36% reported that changes to the benefits system in the past 2 years had left them worse off. These disadvantages will have been made worse by the effects of the pandemic and the extra pressures experienced by families.

A recent study by the Bevan Foundation found that disabled people were disproportionately poor and affected by the cost of living crisis. For example, they found that over half of disabled people who said that their condition limited them a lot went without heating for some time this winter¹⁴.

It is important to look at the way that poverty affects disabled people in terms of both being able to access assessments and support for other conditions and also how poverty can exacerbate health issues.

Not being able to afford heating, good quality food, living with damp or not being able to afford other treatments can aggravate many long term conditions. In addition, not having access to sick leave, job security, needing to work more hours in harder jobs than one might be able to do safely as well as worries about money will all aggravate both physical and mental health difficulties and may lead to developing mental illnesses.

¹³ <https://www.jrf.org.uk/report/uk-poverty-2018>

¹⁴ <https://www.bevanfoundation.org/wp-content/uploads/2023/02/Snapshot-of-poverty-in-winter-2023.pdf>