

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Deintyddiaeth](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Dentistry](#)

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Ymateb gan: | Response from: Mencap Cymru

Response to the Health & Social Care Committee's inquiry from Mencap Cymru September 2022

Introduction

1. About Mencap: Mencap Cymru's mission is to transform society's attitudes to learning disability and improve the quality of life of people with a learning disability and their families – we want to make Wales the best place to live if you have a learning disability. We provide a range of services including an information and advice helpline, legal support, and support services. We also campaign on the issues that affect people most and seek to influence policy and law to ensure people with a learning disability are protected, included and valued. See more about our work on our website www.mencap.org.uk
2. There are estimated to be around 75,000 people with a learning disability living in Wales, with approximately 15,000 known to social services. This includes people with a wide range of impairment, from people who have a mild or moderate learning disability, who live independently in the community with or without support, to people with profound and multiple learning disabilities who may require support 24 hours a day. Many people with a learning disability also have autism and/or complex physical health needs.
3. Mencap Cymru provides support to over 300 adults with a learning disability across direct support services in Flintshire, Wrexham, Denbighshire, Ceredigion, Pembrokeshire, Carmarthenshire, Blaenau Gwent and Powys. This is a mixture of supported living and outreach activities.
4. Mencap Cymru has a network of 23 affiliated groups providing leisure opportunities through volunteer models, and commissioned services.
5. Mencap Cymru is funded by Welsh Government to provide the Wales Learning Disability Helpline. The free service operates 9 to 5 Monday to Friday, including bank holidays. We employ three regional caseworkers who staff the line, and also provide face to face and virtual advice and information to a range of individuals with a learning disability and their family/carers.

6. Our response comprises of stories gathered from individuals using our day service in Powys, direct support services in Northeast Wales, and a local Mencap Group in North Wales.

People with a learning disability and oral health

7. People with a learning disability access dental care in a variety of settings. Some people can see a general dental practitioner, but others who may require more support, or who have more complex dental, physical and behavioural needs access special care through a community dental team, or a hospital dental service. Typically, people may be under the care of a community dentist, then referred to a hospital team if they require IV sedation or a general anaesthetic. These arrangements often depend on the availability of local general practitioners and the waiting list for the community dental teams.
8. Wales-specific data around oral health for people with a learning disability is sparse. Data from England suggest that people with a learning disability are more likely to have poor oral health than the general population, including higher rates of gum disease, missing teeth and greater unmet oral health needs (PHE 2019). Due to physical, cognitive, sensory or behavioural issues people with a learning disability may need more support to establish and maintain an oral health routine, or to access dental treatment. Research suggests that between 40-60% of people with a learning disability will struggle to cope with dental treatment when required (PHE 2019). Support to access services may be required from the dental services themselves, but also from family carers and support workers.
9. Poor oral health can have serious physical, psychological and social consequences for people with a learning disability (PHE 2019), of particular note is the link to respiratory infections, which were identified as the third highest cause of death of all deaths reviewed by the Learning Disability Mortality Review in 2020-21 ([LeDeR annual report, 2021](#)).

Barriers to accessing care for people with a learning disability and their family/carers

10. In North Wales, our consultations suggested a divide between access to dentistry depending on your level of need and geographical location within the health board. We have been told by several carers that they are on a waiting list for either a surgery or community team, but they have heard nothing for more than eighteen months, leaving them reliant on emergency care. The inability to find an NHS Dentist, or to get an appointment with one will no doubt impact the health and well-being not only of individuals, but of their family/carers.
11. Some patients in Ynys Mon have called up looking for a dentist only to be told that the nearest one is in Colwyn Bay, or even Wrexham. Travelling such a long distance can exacerbate anxiety connected to dental treatments, potentially resulting in missed appointments resulting in worse outcomes further down the line.

12. For many of the people we spoke to, the distance to their dental surgery was minimal. But it's clear that those in North West Wales are having to travel further due to a lack of available dental services.
13. One parent and her two learning disabled sons experienced major emergency dental surgery during the COVID pandemic but have not been able to have a follow-up appointment. They are registered with an NHS dentist, however their dentist semi-retired and they are now without a practice. One of her adult children has not seen a dentist for six years.

Waiting Lists

14. It's clear that for many waiting a long time to be seen by a dentist is now a fact of life. Those who shared their stories in North West Wales were waiting in excess of 18 months for check ups, or to be placed with the community dental team.
15. Without regular check-ups people with a learning disability could be at greater risk of developing serious oral health issues, and associated conditions including respiratory and heart issues.
16. The wait associated with community health teams is forcing families to consider one of two paths; private treatment or no treatment. Some are paying for their children to get private treatment, fearful that to leave them without oral care would leave them in poor health. Others simply do not receive any regular dental care, relying on out of hours emergency treatment when problems become acute.
17. A parent was told that despite their son's autism he was unlikely to get onto to a community dental team list as 'he doesn't present as having a learning disability'. Their son often displays distress getting into the dental chair. They were able to get him into a dental surgery where he feels comfortable, and staff make him feel calm. However, they were recently sent an appointment for a check-up but had to cancel at the last minute. They were told that there would then be an eighteen-month wait for another check-up appointment.
18. One grandparent of a six-year-old autistic child has to pay £34 each time for their grandchild to have access to a private dentist. No NHS surgery would take the child on. The grandparent took their grandson to their own NHS check-up to acclimatise him to the environment and the dentist said "I'm not treating him, I can't cope with an autistic child". The dentist said they would refer the boy to the hospital-based team but did not. They eventually found a dentist who would refer their grandson to the community dental team, but they would only do so if the boy became a private patient in the meantime.

The cost of getting dental care

19. One parent has a son who recently turned 18. They believed that because their son has a learning disability, they would continue to receive free dental treatment. Their dentist explained that because he did not receive the right benefits, that he would in fact have to pay for treatment now. Because her son doesn't have a paid job (only 6% of people with a learning disability are estimated to) she will have to find the money to pay the bill.
20. People with a learning disability pay a premium to live, spending on average £538 more for things like energy and transport. (Scope, 2019). With this in mind, many of the people we consulted expressed surprise that free dental treatment was not available for all people with a learning disability, regardless of their benefits entitlement. This means that the burden of these additional dental costs fall on already over-stretched carers who must pay for their adult children not in receipt of the right benefits.

Communications.

21. People with a learning disability often face negative perceptions and attitudes from the general public.
22. The impact of these perceptions are often felt in healthcare settings. The death of Paul Ridd was attributed to neglect on the part of hospital staff. *"It is clear that the individual needs of Paul were not addressed and the fact Paul had physical and mental disabilities was not taken into account with this in mind"*. (Ombudsman's Report into the death of Paul Ridd) Some of our consultations around dentistry suggests that the needs of dental patients with a disability are not considered when communicating with individuals.
23. Many parent/carers had a story to tell about a dentist, or receptionist who did not treat their child with respect, not taking into account a person's disability when communicating directly, or with parent/carers. Some dental staff were outright hostile to the idea of treating someone with a learning disability or autism, as we have outlined above. Dental treatment can represent a traumatic experience for many people with a learning disability. Fear over procedures and the clinical setting can be exacerbated by dental staff who do not communicate with understanding or compassion.
24. In addition to the cases outline in previous sections, one parent was told by an irritated dentist to keep their child still whilst they tried to check their son's mouth. The suggestion of restraint was unhelpful and unprofessional.
25. Others struggled communicating in a professional manner when people displayed behaviours as a result of not being made to feel comfortable in the dental setting.
26. There are pockets of good practice, with individuals identifying a number of young, newer dentists who are excellent communicators. These new dentists do not tend to

stay in a service very long before moving on, meaning they are unable to build relationships with their patients.

Recommendations

27. The Paul Ridd Mandatory training has been rolled out for staff within NHS hospital settings to some success. Mencap Cymru and the Paul Ridd Foundation have also been successful in campaigning to have this rolled out to call-handlers for the emergency services. We feel that this training, or something similar needs to be rolled out to all dentistry staff. This will allow them to communicate in a more accessible way, to better understand people's needs and the behaviours associated with an anxiety-filled trip to the dentist.
28. There was also support within the groups consulted to the idea of extending health passports to cover dental settings, or to create a bespoke passport for dental treatment. This would allow all staff in dental settings to pause and reflect on how they address the needs of learning-disabled patients.
29. We would like to see all people with a learning disability qualify for free dental treatment, regardless of benefit entitlement. Whilst this would benefit a relatively small number of people, it will reduce the burden of paying for these bills which often fall on already stretched families.
30. People with a learning disability, their family/carers would like to see check-ups remain at every six months to ensure that things are picked up early and health inequalities are not widened.
31. There should be a programme to help desensitize people to the sensation of visiting a dentist. This is not restricted to the environment, but the physical sensations of having your teeth brushed, having water jets in your teeth and having things touching the inside of your mouth. This kind of work can really help put people at ease with their dentist, which could help reduce the need for people to see specialist teams.
32. There should be greater monitoring of the oral health of people with a learning disability and the impact of this on overall health and well-being.