



Supporting People With Learning Disabilities to Stay Healthy

In February and March 2025 we visited Bridgend People First and Cwm Taf People First groups to find out how people with learning disabilities experience health and social care services.

18 people with learning disabilities took part in interactive workshops.



What did we do?

We explored helpful and unhelpful behaviours that group members had experienced when accessing health and social care services.

We discussed whether group members knew what to do if they felt unwell or needed help

We role played scenarios to demonstrate the different types of communication people with learning disabilities experience when speaking with doctors

What we heard from the groups

85%

knew how to keep themselves healthy but not all of the participants understood what to do if they are unwell, but they knew who to ask for help.

90%

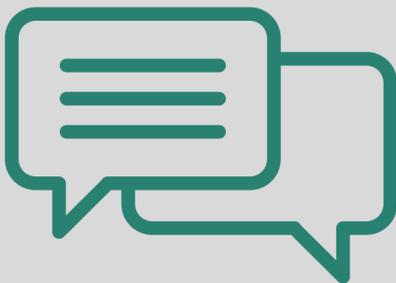
said that medical professionals helped them to understand what they tell them during appointments but they had all (100%) experienced situations where confusing language and jargon was used.

100%

knew that they should have an annual health check with their GP but 60% had not received an annual health check within the past 12 months.

100%

had experienced a situation where a medical professional had spoken to the person accompanying them (family member/social worker/carer/friend) rather than speaking to them directly during appointments.



What we heard from the groups

100% who access social care said that they knew who their social worker is and that they used straightforward language when they communicate, although there was 1 participant who had not heard from their social worker in over 2 years and was not sure if they still had access to support from the local authority.

100% of the participants felt that there should be more opportunities for people with learning disabilities to take part in activities in the community.



Helpful Behaviours



Clear verbal communication using simple language not jargon



Eye contact and open body language



Speaking directly to the patient not their support worker/family members



Repeating explanations and checking understanding particularly when talking about medications and medical procedures



Explain what is going to happen step by step so the patient knows what to expect



Continuity of care where possible so that the patient gets to know a medical practitioner/social worker and they understand their needs



Kindness and patience



Recognition of reasonable adjustments and preferences

Unhelpful Behaviours



Using jargon and specialist terminology without explanation



Not giving patients the additional time they may need to communicate and understand



Expecting people with learning disabilities to be able to sit still for long periods of time



Lack of ongoing communication – what happens next? What to expect.



Not being prepared – when practitioners have not read the medical history to understand the reasonable adjustments needed



Leaving patients to wait for long times without explaining why and not checking in with them



Making patients feel rushed

Health Profile

A health profile is an easy read document that provides nurses and clinicians with essential medical information about a patient with learning disabilities. It encourages staff to make any reasonable adjustments to make medical visits a better experience.



You can find out more at [Health Profile - Paul Ridd Foundation](#)



Cwm Taf People First explained to us that they have been raising awareness of the importance of using a Health Profile and have attended Royal Glamorgan Hospital to speak about their use.

Concerns that people raised with us

Lack of spaces and activities for people with learning disabilities to get together

Impact of local authority cuts on services for people with learning disabilities

Difficulty travelling for care and to attend activities

Negative experiences whilst attending the Emergency Department at Royal Glamorgan Hospital

Lack of awareness of reasonable adjustments from some medical practitioners left patients with learning disabilities feeling frustrated, embarrassed and confused.

Suggestions for Improvements

Use open body language and eye contact

Promote the use of Health Profiles and understanding of reasonable adjustments

If a patient with learning disabilities has to wait a long time, ensure staff check in on them and explain why they are waiting and how long they will need to be there.

Ensure that patients with learning disabilities are given longer appointments so they have time to explain their issues and understand what the doctors are telling them.

Make waiting spaces more friendly for patients who have learning disabilities and neurodiversity (e.g. provide something to focus and distract patients such as fidget toys, music, reading materials)

What happens next?

Llais supports People First in raising awareness of health profiles - our advocacy service has been encouraging clients with learning disabilities to speak to their practitioners about setting up a profile, and we will also make a representation to Cwm Taf Morgannwg UHB to ensure that the health board is aware of the benefits of health profiles.

Concerns that have been raised will be shared with the CTM UHB and local authorities for feedback.

Group members who wanted to share their experiences have prepared patient stories which have been recorded and will be shared with the health board and local authorities.

Thank you

Thank you to Cwm Taf and Bridgend People First groups for sharing your experiences with us.