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GOGLEDD CYMRU
NORTH WALES
REGIONAL PARTNERSHIP BOARD

Learning disabilities – Evidence summary

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Disclaimer: This evidence summary includes relevant literature identified from searches on the above topic. It is not an exhaustive list, it presents key finding and not recommendations for practice.

Overview

This report looks at the issues that are faced by people with learning disabilities and the barriers they might face when trying to access health and care services. It then looks at additional issues that specific groups of people with learning disabilities may experience. These include people with learning disabilities who from ethnic minorities, older people, and parents.

The report focuses on research and reports based mainly on Wales or the UK. Research from elsewhere is only included when relevant.

Challenges faced by people with learning disabilities

People with learning disabilities may face additional challenges. These might include:

- A lack of appropriate care and support in the community [1]
- Lack of tenancy support, including with money and bills, accessible information, support when things go wrong and to find a place and move in [2,3]
- Accommodation not having the necessary adjustments [3]
- Facing bullying, social exclusion, and discrimination [4–6]
- Being more likely to experience health problems [4,7]
- Being more likely to experience multiple health conditions [4,7–9]
- Being at increased risk of dementia [7]
- Having reduced life expectancy and being at risk of avoidable deaths [7,10,11]
- Having mental health problems [6–9]
- Having less active social lives / fewer friendships / feel isolated [4,6]
- Not being as integrated into their community [4]
- Lacking autonomy / opportunities to make informed choices [3,4]
- Their views not being sought, or being disregarded or ignored [8]
- Being less likely to be in employment [5]
- Lacking opportunities to live independent lives, work and home tasks [4]
- Exhibiting challenging behaviours [4]
- Being more vulnerable to abuse [5]
- Having difficulties accessing leisure activities [6]
- Lacking of access to accessible technology [6]
- Having less sleep and / or poorer quality sleep [12]

It is important to note that people with learning disabilities are all unique and some may experience more disadvantage than others. The level of disadvantage a person experiences is often related to the level of disability a person has.[4]

Challenges accessing health and care services

Many people with learning disabilities have positive experiences, receiving good care and support.[8] However, some people with learning disabilities can face many barriers to accessing good quality health and care. These might include:

- Not receiving the support they need [3,8,13]
- Carer breaks (respite) for family / carers not always being readily available [8]
- Limited choice for residential care / housing which may be far from home, inappropriate, and their needs and preferences not being considered [2,8,13,14]
- Issues or a lack of provision occurring when transitioning to adult services / accessing services as an adult [6,8,9]
- Being difficult for them to complain about their care [8]
- Having language and communication barriers when accessing services [6,10]
- A lack of accessible transport links [7]
- Patients not being identified as having learning disabilities [7]
- Staff having little understanding about learning disabilities [7]
- Failure to recognise that a person with learning disabilities is unwell [7,8,11]
- Poorer health outcomes due to delayed diagnosis / treatment due to diagnostic overshadowing (the assumption symptoms are related to their learning disability) [11]
- Not getting the correct diagnosis [7]
- Anxiety or a lack of confidence for people with a learning disability [7]
- Lack of joint working from different care providers [7]
- Lack of continuity of care can be unsettling / problematic [8,13]
- Not enough involvement allowed from carers [7]
- Inadequate aftercare or follow-up care [7]
- Being less likely to access preventative care such as breast checks, cervical smears, colorectal cancer screenings, and immunisations [7]
- Lack of reasonable adjustments [7,11]
- Being prescribed medication they don’t need to manage their behaviour [11]
- Being denied treatment due to assumptions about them not being able to tolerate the treatment, for example chemotherapy [11]
- Lack of forward planning when a person can no longer remain in the family home, for example as their carer is ageing [13]

People with learning disabilities may find that mainstream mental health services are unsuitable for them. This may include:

- Therapies not being adapted to meet their needs [9]
- Staff not trained to support people with learning disabilities [9]
- Being denied access, as they don't meet the threshold [9]
- Being sent to learning disability services who don't offer mental health services [9]
- Diagnostic overshadowing, with symptoms mistaken for characteristics of learning disabilities [9]

It has also been raised as an issue that some people with learning disabilities have been placed into secure hospitals when it is not appropriate. Issues might include:

- Being admitted despite not having a mental health issue [1,10]
- Being admitted even though it is not what is best for them [1]
- Being admitted due to lack of appropriate housing / support [1]
- Staying longer than necessary [1]
- Being admitted into hospitals far from home / isolated from family [1]
- Being more likely to be subjected to restrictive practices, such as restraint, long-term segregation, and seclusion [1]
- Staff having limited experience of people with learning disabilities [1]

Challenges faced by specific groups of people with learning disabilities

Ethnic minorities

People from ethnic minorities who have learning disabilities can face additional challenges. These might include:

- Having a further reduced life expectancy and increased risk of avoidable deaths compared to others with learning disabilities [11]
- Cultural context not being considered when offering choices [15]
- Feeling disempowered / lack opportunity to contribute to decisions [15]
- Not feeling confident to speak up fearing this may impact their care [15]
- Experiencing stigma or fearing stigma from their community [15,16]
- Being more lonely and isolated due to the impact of stigma [15,16]
- Not accepting the diagnosis of having learning disabilities [16]
- Experiencing language barriers [15,16]
- Experiencing unequal treatment due to ethnic discrimination [16]
- Experiencing barriers to accessing religious activities due to the background of their support staff [16]
- Difficulties when transitioning from child to adult services [16]

Older people

While many older people with learning disabilities live fulfilling and well supported lives[13], some can face additional challenges. These might include:

- Having to move from a place they have been living in for many years [8]
- Less family involvement due to family passing away or having health issues [8]
- Being at higher risk of being isolated [8]
- Needing staff to advocate for them [8]
- Agencies not working together to provide help and support [13]
- Identification of dementia being delayed [13,17]
- A lack of appropriate housing [13]
- Having limited choice about where they live, who with, who supports them, and how they spend their time [13]
- Services not thinking about how to support a person as they grow older [13]
- Prevalence of mental health issues increasing with age [17]

Parents

People with learning disabilities can be capable and loving parents, and the way we view them as parents has started to transform over time to reflect this viewpoint[18], however, they may still face challenges. These might include:

- Staff not having sufficient knowledge / training to support them [19]
- Not having been identified as having learning disabilities [19,20]
- Experiencing stigma or judgement, having to prove themselves [19]
- Fearing judgement or even losing their child [19]
- Not receiving the support they need [19,20]
- Being more likely to have children removed from their care [19]
- Lacking parenting role models and support networks [19]
- Social workers lacking training / confidence [20]
- Adult and child services not working together effectively [20]
- Lack of advocacy services when involved with social care [20]
- Lack of support when children are removed [20]

Mothers

Mothers with learning disabilities might face specific challenges. These might include:

- Not being included in discussions about their antenatal care [21]
- Needing help to understand some aspects of pregnancy and birth [21]
- Experiencing language and communication barriers when receiving care [21]
- Lacking autonomy in taking care of their child [22]
- Mother and child sometimes having conflicting needs [22]
- Internalising stigma and doubt themselves [22]
- Fears around having their child removed / being judged incompetent [21,22]
- Higher risk of adverse obstetric and pregnancy outcomes [23]
- Higher risk of premature birth, and death of the baby before and after birth [23]
- Longer hospital stays [23]
- Experiencing negative reactions to their pregnancy announcements [21]

Fathers

Fathers with learning disabilities might face specific challenges. These might include:

- Needing more support with parenting [18]
- Experiencing periods of absence from their children [18]
- Services not always engaging with them, focus tends to be on mothers [18]

Search strategy

Basic searches of Senedd Research, Gov.wales, Insight Collective, and Google were completed. A detailed search of Scopus was also completed.

Scopus

"learning difficult*" or "learning disabilit*" or "intellectual difficult*" or "intellectual disabilit*" (abstract)
AND
need* OR requirement* OR demand* OR support* OR assistance OR help OR barrier* OR challenge* OR obstacle* OR issue* OR problem* OR difficult* OR concern* OR risk* (abstract)
AND
england OR scotland OR wales OR "united kingdom" OR UK OR Britain (affiliation country)
Limit: 2021-2026

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