

## CB-NSG November 2025 – Neighbourhood Health

### *Summary of workshop discussion and agreed actions*

#### Discussion

#### How can we ensure that people with learning disabilities and their families are key parts of the neighbourhood health model?

Attendees highlighted the need to ensure that people with lived experience are not only represented, but are key figures, at every level of integrated care boards (ICBs). Similar to/adapting work by Rethink Mental Illness to facilitate involvement of experts by experience in improving community mental health services, having people with learning disabilities and family carers represented throughout ICBs (e.g., ensuring services are suitable and that policies are inclusive and coproduced) would support the development of services and policies that reduce health inequalities. Having a coproduction strategy – setting out how ICBs and other bodies need to involve people with lived experience in developing neighbourhood health – would be an avenue to ensuring this representation.

Attendees highlighted that meeting the needs of people with learning disabilities whose behaviour challenges needs to be considered from the outset, rather than setting up neighbourhood health models and then thinking about how they can meet the needs of people with learning disabilities.

#### What kind of workforce/infrastructure needs to be included in neighbourhood health to achieve the right outcomes for people with learning disabilities whose behaviour challenges?

Attendees raised concerns that the decline in numbers of learning disability nurses, and the closure of many learning disability nursing courses, would negatively impact the development of neighbourhood health that meets the needs of people with learning disabilities whose behaviour challenges.

Attendees also highlighted that, for people with severe learning disabilities whose behaviour challenges, there needs to be access to specialist services within the community. Concerns were raised that the emphasis on mainstream services at the expense of specialist services/specialists that sit within wider services could result in further barriers to accessing appropriate healthcare, and emphasised that specialist

teams need “a seat at the table” to advocate for this group of people. The need for specialist services, or specialists within wider services, was also discussed in relation to rural areas, where services may be covering a wider geographical area – if a specialist team needs to reach people across a wider geographical area, then there needs to be sufficient funding built in to cover e.g., transport costs (funding per head would not necessarily meet these and could exacerbate health inequalities, particularly for people who may not be able to travel themselves). A similar issue was raised around transport and other infrastructure which is not directly part of neighbourhood health, but is a key facilitator or barrier to it – if there is not accessible transport, then someone may not be able to access neighbourhood health services with equity.

A key issue discussed was the lack of an evidence base for what makes a real difference in terms of addressing health inequalities for people with learning disabilities, such as premature mortality. Without a strong evidence base, it is difficult to identify what is needed in neighbourhood health systems to address these health inequalities. However, attendees recognised that there is some existing good practice, as well as better information about what creates barriers to accessing healthcare, which could be explored further. An approach currently being piloted in the Black Country is a register, similar to the Dynamic Support Register, for physical health issues, which also involves keyworkers that work with individuals to provide wraparound support; outcomes will be measured and evaluated to see if this approach improves health outcomes, but as it is an unfunded approach there is not funding for it to be evaluated as a full research study.

Data infrastructure was also highlighted as something that should be built into neighbourhood health models. Attendees highlighted the difficulty that a lack of data, e.g., on how often people with learning disabilities are accessing GPs or emergency care, causes when trying to identify what factors/approaches reduce health inequalities. Likewise, when different teams use different recording systems, this prevents information from being shared; as well as making it harder to identify health issues, this can contribute to [systems-generated trauma](#).

The Children and Young People’s Neighbourhood Health Implementation Group was welcomed, but attendees were concerned that there is not a corresponding group for adults. They also highlighted that implementation needs to be all-age, and raised concerns about the transition cliff-edge between children’s and adult services. Developing neighbourhood health models is an opportunity to develop a ‘whole life’ approach which could help address the problems that young people face during transition.

Attendees also highlighted the need for the workforce to have sufficient knowledge of learning disabilities to tackle diagnostic overshadowing, as well as embedding a culture that focuses on how people with learning disabilities can live good lives, rather than assumptions that poorer life expectancy/health inequalities are to be expected. Part of this involves empowering families and ensuring that they have the right knowledge to be able to push for better outcomes for their relatives.

## Working together to improve neighbourhood health – actions

### Existing information and support for people with learning disabilities whose behaviour challenges and their families

Attendees felt that the pilot of the TAP device for blood tests without the use of needles was a good example of how care closer to home (as part of the neighbourhood health model) could be used to improve outcomes for people with learning disabilities, and that information about how this offers a positive alternative to standard blood tests should be shared so that a) families and b) medical professionals were aware that it is an option which could be explored. As it is a pilot, this is not currently available to support people with learning disabilities in all areas. One attendee confirmed that they would disseminate this information within their organisation to increase awareness of this option.

### Key systemic issue(s) that need to be tackled by the CB-NSG and other partners

Attendees identified the need to:

- a) **Address the fall in numbers of learning disability nurses**, and courses for training learning disability nurses – to ensure that people with learning disabilities whose behaviour challenges and their families have access to a trained learning disability nurse who can communicate with them and act as a liaison/coordinator
- b) Improve integration and coordination between health services by **implementing consistent reporting systems** (either using the same systems, or establishing processes for sharing information between different systems) – reducing the burden on individuals/families to share their experiences multiple times and enabling better coordination and identification of needs
- c) Ensure that changes to ICBs do not result in the loss of key parts of the workforce, such as lived experience co-ordinators and PBS practitioners

## Practical solutions which could be implemented in the short-term to make a difference

Attendees identified:

- a) Developing a **coproduction strategy** to ensure that people with learning disabilities and family carers are represented across ICBs
- b) Creating a collection of **case studies that showcase good practice** to be shared with neighbourhood teams
- c) **Increasing the evidence base to demonstrate cost-savings** on a financial and human level
- d) Changing the **language** used by health professionals and organisations to reduce stigma and parent-blame – i.e., not using “hard-to-reach”

During the discussion, it was agreed that framing the need for the development of neighbourhood health services to engage with and meet the specific needs of people with learning disabilities whose behaviour challenges through the lens of health inequalities (e.g., [Core20PLUS5 for adults](#), [Core20PLUS5 for children and young people](#)) could help the people developing these services to understand the need for them to meet the needs of this population.

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