

## **South West Learning Disabilities Collaborative - Impact Report (short version)**

### **Overview**

Health Innovation West of England won BMJ (British Medical Journal) and HSJ (Health Services Journal) awards in 2018 for the use of NEWS2 (National Early Warning Score) to support the identification and management of the acutely unwell patient. As part of this work the team had become aware of the poor outcomes for people with a learning disability, and particularly the challenges of identifying and communicating concern if a person becomes unwell.

Following discussions with NHS England South West Learning Disability and Autism team, it was decided to establish the West of England Learning Disability Collaborative. Initially the collaborative covered the West of England footprint, but in 2022 NHS England formalised the funding and the South West Learning Disabilities Collaborative (SWLDC) was formed.

The aims of this collaborative are simple and have not changed: to improve the health outcomes of people with a learning disability.

The SWLDC provides a valuable function in connecting people across the region and beyond who have an interest in improving outcomes for people with a learning disability. There is no national forum or mechanism for people to share projects, resources, and experiences. Events ran by the collaborative facilitate introductions and spread awareness of activity around the country.

### **Impacts**

#### **Webinars**

Since 2022, 14 webinars and workshops have been delivered to a range of audiences, with attendees spreading across the country due to speaker locations. Speakers frequently note there is no equivalent collaborative in their areas. The model is low cost, easily accessible, and the learning is easy to share, suggesting potential for spread to other regions.

#### **Train the trainer (spotting deterioration)**

This training for paid and unpaid carers helps them spot signs of deterioration and escalate concerns. It was co-created with experts with lived experience. Over 9000 carers were trained using this model in 3 months. Videos supporting this training continue to be widely shared across the NHS, with over 350,000 views (at the time of writing), believed to be the most widely shared content developed by people with a learning disability. An evaluation found that carers felt empowered in conversations with clinicians. The training was Commissioned by NHSE to address the inequality of people with a learning disability being much more likely to die from COVID-19.

#### **Annual health check resources**

A series of videos were produced for NHS England on Annual Health Checks, coproduced with members of the Misfits Theatre Company (actors with lived experience). Hosted on the

Health Innovation Network YouTube Channel, they have been viewed over 10,000 times and are linked on the LeDeR - Healthy Lifestyle web page.

#### Supporting the wider NHSE agenda

The collaborative worked with NHS England South West to support the roll out of Virtual Wards and NHS@Home.

SWLDC provided case studies on challenges faced by people with a learning disability when asking for a review under Martha's Rule. The collaborative is also working with NHSE and eLfH to develop training on Martha's Rule, ensuring a scenario highlighting issues for people with learning disabilities is included.

SWLDC has developed relationships with care providers, e.g. by joining Silva Care's parent and carer forum, providing information about annual health checks and asking for reasonable adjustments in a healthcare setting.

Emily Richardson, Clinical Project Officer at Sirona Care and Health, is developing a pathway on point of care testing (CVD) and we are working with her to support this.

#### Other

The SWLDC collaborated on a training module on sepsis and people with a learning disability which will be available in Spring 2025.

Dr. Alison Tavaré serves as the Clinical Lead of the SWLDC. She represents the collaborative at various related groups and has co-authored numerous publications related to learning disabilities.

#### **Next steps**

The collaborative's strength is its ability to be reactive to emerging and evolving NHS priorities, to bring stakeholders together and lead discussions about developing solutions.

It has taken time to develop credibility and a critical mass of membership from a very broad range of backgrounds. In the last few months, the SWLDC has seen a surge in engagement and appetite for collaboration. This can be harnessed to find care and pathway alternatives to allow an increasing number of people with a learning disability to be looked after in community settings when they become acutely unwell.

There is no other group of stakeholders who could provide such a wide range of expertise and practical know-how.

The collaborative currently has over 500 members, increasing at a rate of around 25% a year. SWLDC members represent a broad range of expertise and include experts by experience, carers and healthcare professional.

The SWLDC and its broad membership is frequently approached with requests for collaboration from a wide number of national organisations.