# KEY THEMES AND RECOMMENDATIONS: ADULTS WITH A LEARNING DISABILITY JSNA

Warwickshire Joint Strategic Needs Assessment 2025



### Adults with a Learning Disability JSNA Summary





- Make reasonable adjustments to ensure people with a learning disability can access services.
- Encourage registration on the GP learning disability register.
- Promote annual health checks.
- Engage with people with a learning disability.
- Regularly record and monitor data in our services.

#### **KEY THEMES**

#### LOCAL POPULATION



This JSNA considers multiple data sources to give an estimate of the population with a learning disability in Warwickshire. All these data sources have caveats but are likely to be under-representing the true prevalence of the number of people with a learning disability in Warwickshire.

Not all people with a learning disability are on a GP register. As a result of this, some of our population in Warwickshire may not be getting the support they are entitled to, such as annual health checks.



It is estimated that, by 2040, there will be an additional 1,500 people with a learning disability in Warwickshire, a total of 12,657 people in 2040 compared to 11,197 in 2024. These figures indicate that around 2.3% of the 18+ population have a learning disability.



There is an under-representation of people from a minority ethnic background accessing services and registered as having a learning disability on the GP register.



There is a disproportionately high representation of young men with a learning disability on both the GP register and accessing services for learning disabilities.

#### HEALTH OF THE POPULATION



People with a learning disability experience health inequalities to a greater extent compared to those without a learning disability. This can be seen in a range of health conditions and risk factors compared to the population without a learning disability, including increased prevalence of:

- Obesity
- Smoking

- Diabetes
- Asthma
- Cardiovascular Disease (CVD)
- Epilepsy
- Chronic Obstructive Pulmonary Disease (COPD)
- Musculoskeletal related conditions
- Mental health conditions
- Dementia



Life expectancy is lower for people with a learning disability. The median age of death for men and women was lower in populations with a learning disability with a 'gap' of 19 and 23 years respectively. Life expectancy is lower still where people with a learning disability are from a minority ethnic background or live in a deprived area. In 2021, the national Learning from Lives and Deaths (LeDeR) programme noted that people with a learning disability were 'dying earlier than they should, many from things which could have been treated or prevented'.



Annual health checks (AHC) help people with a learning disability to stay well and mitigate against health inequalities. In 2023/24, Warwickshire achieved a 76% AHC uptake in its GP registered population aged 14 and over, in line with the local and national target of 75%. The quality and uptake of these should be supported, particularly the delivery of health action plans.



The leading cause of death among the population with a learning disability in Warwickshire whose death was reviewed as part of the LeDeR programme was respiratory conditions. In 2023-24, pneumonia (a respiratory infection that affects the lungs) was classified as a local priority for the Coventry and Warwickshire LeDeR programme.



Smoking is a major cause of chronic obstructive pulmonary disease (COPD), one of the major respiratory diseases. As highlighted above, both smoking and COPD have an increased prevalence in adults with a learning disability.



Cardiovascular conditions were the most likely to be linked to avoidable deaths in adults with learning disabilities, followed by respiratory and cancer deaths. Cardiovascular diseases can be associated with some genetic causes of learning disability, for example, Down Syndrome. However, higher rates may also be explained by other risk factors associated with cardiovascular disease which are more likely in populations with a learning disability. This includes higher rates of obesity and diabetes as well as other lifestyle factors that contribute to a picture of poorer health in those with a learning disability.



Whilst Down syndrome itself is not a learning disability, a person with Down syndrome will have some degree of learning disability, with the level of need varying between individuals. There are conditions that people with Down Syndrome are more likely to experience than both people with a learning disability and those without a learning disability, particularly dementia.



The uptake of cancer screening (breast, cervical, and bowel) is lower in the population with a learning disability compared to the non-learning disability population.



People with a learning disability are identified as a key at-risk group eligible for certain vaccinations. In September 2024, all people with a learning disability are eligible for the pneumococcal vaccine. The uptake of flu vaccinations in adults with a learning disability is lower than the 75% target, especially in younger age groups.



There is a higher incidence of people with a learning disability dying in a hospital setting compared to the population without a learning disability.

#### WIDER DETERMINANTS



Wider or social determinants of health (for example, housing, employment or transport) have a huge impact on people with a learning disability and they need to be considered and addressed to support reducing health inequalities for those with a learning disability and to improve quality of life for this group.



This JSNA mapped engagement recently undertaken with people with a learning disability in Warwickshire, findings of which have been fed into the scope of this document. This engagement highlighted things that are important to people with a learning disability locally, including:

- Having independence
- Having somewhere to go

- Being able to access activities
- Having accessible transport
- Having a good support worker
- Support transitioning between child and adult services
- Employment opportunities
- Having a choice of accommodation

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Making reasonable adjustments can support people with a learning disability to access services, amenities and feel part of their community. Organisations need to consider how to make reasonable adjustments to fulfil their legal obligations under the Equality Act to help ensure people with a learning disability are not disadvantaged.



People with a learning disability were more likely to be living in more deprived areas; this was more marked as people age.



Research nationally highlights that people with a learning disability from ethnic minority backgrounds face a shorter life expectancy than those from a white background. The average age of death for people with a learning disability from an ethnic minority is 34 years, just over half of the average age of death for people with a learning disability from a white background, which is 62.



People with a learning disability may experience difficulties securing the accommodation of their choice, especially if they have more complex care needs. Recent engagement in Warwickshire with people with a learning disability highlighted that being able to choose the right accommodation is important. This includes:

- Having their own house, although this could be living with someone they know such as a friend;
- Living near friends and family;
- Living near green spaces;
- Living near amenities.



Recent engagement in Warwickshire with people with a learning disability highlighted that people wanted support to gain meaningful employment. Several barriers to this were identified including:

- Job application forms and processes can be complicated and can take a lot of time;
- Interviews can cause a lot of anxiety;
- There isn't always transport to get to work;
- Some parts of jobs might be difficult. For example, if there's too much reading or computer work;
- Colleagues may not understand an individuals' disability(s) or needs;
- It can be difficult when there are a lot of day-to-day changes at work.

#### RECOMMENDATIONS

The recommendations from this Joint Strategic Needs Assessment (JSNA) are grouped according to their audience.

During the development of these recommendations several groups were engaged with to help shape them, these include:

- Working in Partnership Learning Disabilities Board
- LeDeR Subgroup
- Learning Disability and Autism Health Inequalities Steering Group
- Learning Disability and Autism Collaborative
- Disability Service Area Meeting

## RECOMMENDATIONS FOR MULTIPLE ORGANISATIONS (SUCH AS THE VOLUNTARY SECTOR, PROVIDERS, LOCAL AUTHORITIES AND NHS PARTNERS)

All organisations have a **duty under the Equality Act** to ensure people with a learning disability can access work, education and services as easily as those without a learning disability. All organisations should therefore:

- Be learning disability aware and support and advocate for changing attitudes to value people with a learning disability as individuals with unique strengths and needs, challenging stigma and discrimination of people with a learning disability.
- Ensure that all services are equipped to support people with a learning disability, including consideration for where there may be multiple health needs. The <u>4 P's</u> <u>Reasonable Adjustments Model</u> should be used to help services anticipate the likely needs of people with a learning disability and make reasonable adjustments.
- Support the development, implementation and uptake of the digital reasonable adjustment flag across the health and care system.
- Ensure all appropriate health and care staff complete The Oliver McGowan Mandatory Training on Learning Disability and Autism to ensure our workforces have the right skills and knowledge to provide safe, compassionate and informed care to people with a learning disability, emphasising the positive impact of early intervention.
- Use this JSNA as a key evidence base when completing Equality Impact Assessments (EqIA) and Health Equity Assessment Tools (HEAT) to ensure systematic recognition of those with a learning disability and appropriate action is identified and embedded as part of these assessments.

- Actively engage with people with a learning disability, including networks and groups that support the learning disability community and their families and carers to ensure the voice of people with a learning disability is present and heard to plan, develop and deliver effective services.
- Engaging with faith and community leaders to support people with a learning disability in different communities is something all services, projects and programmes working with this population need to consider as part of their communication and engagement planning.

All organisations need to **support identifying people with a learning disability** and promote the benefits of being on the **learning disability register**. This should include targeting specific groups including those:

- At transition age (14-18 years) ensuring people with a learning disability are preparing for adulthood.
- Under-represented in the data, including minority ethnic groups, homeless people and older people.

All organisations should take a Making Every Contact Count (MECC) approach by supporting annual health checks. This includes:

- Creating messaging and pathways that are learning disability friendly, promoting and ensuring access to these services for those delivering annual health checks. This should include key health promotion messages around prevention, early identification, treatment and risk factors for the conditions highlighted in this JSNA.
- Identifying proactive opportunities to promote annual health checks to people with a learning disability.
- The Working in Partnership with Learning Disabilities Board have taken an action to produce annual health check promotional material for both Warwickshire and Coventry.
  All organisations should look for opportunities to use this material.

All organisations to **improve data collection**, **recording and monitoring of those with a learning disability**. As well as the legal duty under the Equality Act, NHS England has placed <u>duties</u> on all NHS organisations to collect, analyse and publish information on health inequalities, including those with a learning disability, and set out how they will respond to addressing these inequalities.

All organisations should **promote the use of Health and Social Care Passports**, formally known as hospital passports, once the current work redesigning these is completed (led by Coventry & Warwickshire Partnership Trust) to ensure that people with a learning disability are well supported.

All organisations need to continue to **support the work of Learning from Lives and Deaths (LeDeR)** and respond to their findings and recommendations. LeDeR is a programme that reviews the deaths of people with learning disabilities and autism to improve their health and reduce health inequalities.

All organisations need to address the health inequalities experienced by this population where there are opportunities to do so, ensuring that workstreams that support health and wellbeing are learning disability friendly.

All organisations need to work to **improve the uptake of cancer screening** for those with a learning disability via health promotion as a critical way to help reduce and address health inequalities that those with a learning disability face. This includes:

 Addressing barriers to cancer screening appointments raised by people with a learning disability in Warwickshire through engagement with Grapevine as highlighted in this report.

- This report has made specific reference to the low uptake in breast, cervical and bowel cancer screening for those with a learning disability. Although not directly referenced in this JSNA, there are a number of other screening programmes, such as prostate, that should also be promoted to improve uptake.
- Promoting the uptake of the <u>Coventry & Warwickshire Lung Health Check</u> programme which screens people who smoke or have ever smoked for lung cancer.

All organisations need to support people with a learning disability to get the vaccinations they are eligible for. This includes:

- The flu vaccine, where people with a learning disability are identified as a clinically 'at risk' group but currently this population does not hit the 75% target uptake. Younger age groups should be particularly targeted as they have the lowest uptake.
- The pneumococcal vaccine, where guidance has recently changed (as of September 2024) as part of the immunisation schedule. This should support the uptake of the pneumococcal vaccine for people with a learning disability, although this is yet to be reflected in <u>The Green Book</u> for health professionals and immunisation practitioners.
- The COVID-19 vaccine which is offered to anyone on the learning disability register.
- Ensuring people with a learning disability are supported to get new vaccines in future.

All organisations need to **promote advanced care planning** for people with a learning disability, having conversations about end-of-life care at the appropriate time. This should be promoted through the systemwide all age Palliative and End-of-Life Care strategy led by the Coventry & Warwickshire ICB.

Given the evidence that people with a learning disability are more likely to experience poor mental health, all organisations should look for opportunities to maximise mental health and wellbeing support. This includes:

• Ensuring mental health and wellbeing support pathways are learning disabled friendly and promoting these with those who may refer (such as GPs).

- A continued focus on reducing hospital admissions for mental health conditions, supporting mental health needs in the community where possible.
- Targeted work on mental health and wellbeing for those living in the most deprived areas of county.
- As identified in the NHS Long Term Plan, support and adhere to stopping over medication of people with a learning disability and autistic people (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP) agendas to stop inappropriate prescribing of psychotropic medications.

#### **RECOMMENDATIONS FOR LOCAL AUTHORITIES**

The intelligence and insight from this JSNA will be **included in the life course approach currently being scoped** as part of the future work programme from April 2025 onwards, ensuring we continue to have a timely evidence base for this population to support appropriate decision making across partners of the Health and Wellbeing Board.

**Promote healthy lifestyles and referral pathways** for services that support health and wellbeing, including health risk factors, **ensuring messaging and information is learning disability friendly**. These should be promoted with professionals who support people with a learning disability, in line with the MECC approach highlighted in the overarching recommendations.

**Target communications around vaccination uptake**, engaging with social workers, support workers and care providers (social care teams) to build into annual reviews.

This JSNA has acknowledged that people with a learning disability live in a range of different housing options. We need to understand how to best influence all housing providers to

ensure housing is appropriate for those with learning disabilities and adhere to the building for life principles.

#### **RECOMMENDATIONS FOR ALL COMMISSIONERS OF SERVICES ACROSS WARWICKSHIRE**

Commissioners have a responsibility to consider these findings and recommendations when creating market position statements, reviewing services and developing future commissioning models.

Commissioners to promote these findings and recommendations with providers, services and organisations they work with and work with key stakeholders to adopt and respond to them.

Commissioners to ensure services and providers have accurate recording set up to capture interactions with people with a learning disability. Commissioners of all services should be able to report on people with a learning disability by ensuring appropriate data is being collected and this data should be regularly monitored.

Commissioners should support the dissemination of health promotion communications including vaccination and screening communications.

Ensure provider staff are trained and equipped to support people with a learning disability.

Consideration needs to be given to the **provision of care homes**, **supported living and community offers for working age adults with dementia and frailty** due to early onset of conditions in this population meaning support may be required at a younger age.

Commissioners should ensure services are designed to allow accessible pathways from annual health checks into commissioned services.

Commissioners should **promote annual health checks in different settings**, for example in residential homes, supported living accommodation and nursing homes.

Commissioners should ensure services are promoting independence and empowerment including a statement in all relevant service specifications.

Commissioners to **support transitions**, ensuring people with a learning disability are prepared for adulthood, as highlighted by engagement mapped in this JSNA.

#### **RECOMMENDATIONS FOR PRIMARY AND SECONDARY CARE**

Findings from this JSNA should be shared with primary and secondary care, particularly highlighting the size of the expected population with a learning disability.

Primary care should **proactively cleanse their learning disability registers annually**. This should include ensuring that coding for a learning disability is correct and consistent.

Colleagues in CWPT should support primary care in this to ensure registers are cleansed accurately.

GPs should seek to become accredited with the Learning Disability Friendly Badge.

Promote and work towards the recommendations made in the "Learning Disability Annual Health Checks, 2023/24 Quality and Under-served Population Project" report from July 2024, available here on the <u>Coventry and Warwickshire ICS website</u>.

Primary care to **support improving the uptake of all vaccinations** for those with a learning disability through promotion in annual health checks and other appointments.

We need to create strong links into medical examiner officer (MEO) teams to support capturing community deaths, enabling accurate reporting into the LeDeR programme for learning disability and autism deaths.

Ensure primary care are **aware of the dementia diagnosis pathway** through the Community Learning Disability Team within CWPT, who have specific tools to help diagnose dementia in people with a learning disability.

Annual health checks to be used as an opportunity to ensure people with a learning disability are not receiving unnecessary medication in line with STOMP and STAMP agenda.